

CaRE for LUTO – Registry

User Manual





Table of contents

1) Introduction	
(1) About REDCap	page 3
(2) Getting Started	page 3
(3) Navigating in REDCap	page 3
1.3.1 Add new Records	page 4
1.3.2 Edit existing Records	page 5
1.3.3 Navigating within a data collection	page 6
1.3.4 Adding to existing Follow Up Records	page 6
(4) Saving Data	page 7
2) General information	page 8
(1) * must provide value	page 8
(2) Units to be documented	page 8
(3) Value does not fit the standards	page 9
(4) Reset your entry	page 9
3) Record ID	page 10

[Overview of the projects](#)

4) LUTO Prenatal	page 11
5) LUTO Postnatal	page 35
6) LUTO Follow Up	page 50



1. Introduction

(1) About REDCap

Research Electronic Data Capture is a secure, web-based application, specifically geared to support online as well as offline data capture for research studies.

Please find more information about the REDCap program on their website:

projectredcap.org

(2) Getting started

Access to the REDCap system with your very own user account must be requested through the University Hospital of Erlangen.

You can find the respective forms to fill out on our website/ in the Email we sent you. Please only fill out the highlighted fields.

When you have entered all of your data, please email your user application to

careforluto.KI@uk-erlangen.de.

You will be informed by email when your user account is completely set up and you will be granted access to the following Projects:

Pränatalvisite LUTO

LUTO Postnatal

LUTO Follow Up

Once you have access to the projects, you will be assigned the user role “Data Entry Person” and a Data Access Group for your location. This role and the placement in your data access group enable you to view, enter, edit and delete all data which has been entered through your location.

(3) Navigating in REDCap

Once you have logged into your REDCap account, you will be shown an overview of the projects you have been granted access to.

REDCap Home My Projects Help & FAQ Training Videos Send-it Logged in as profile Log out

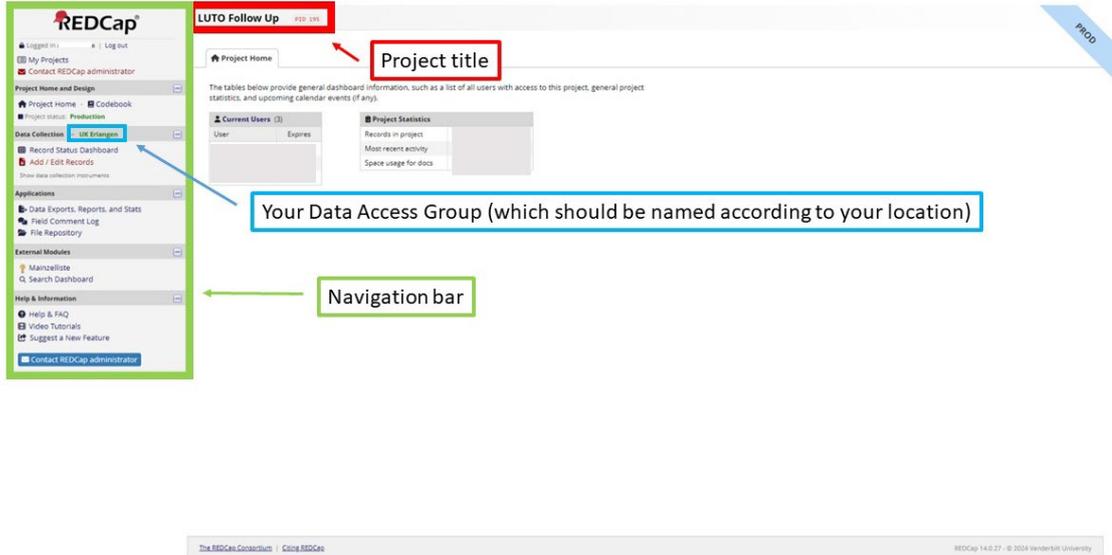
Listed below are the REDCap projects to which you currently have access. Click the project title to open the project. [Read more](#) To review which users still have access to your projects, visit the [User Access Dashboard](#).

Project Title	PID	Records	Fields	Instruments	Type	Status
LUTO Follow Up	195	0	212	18 forms		
LUTO Postnatal	196	0	134	8 forms		
Pränatalvisite LUTO	201	1	293	18 forms		

REDCap 14.0.27 - © 2024 Vanderbilt University

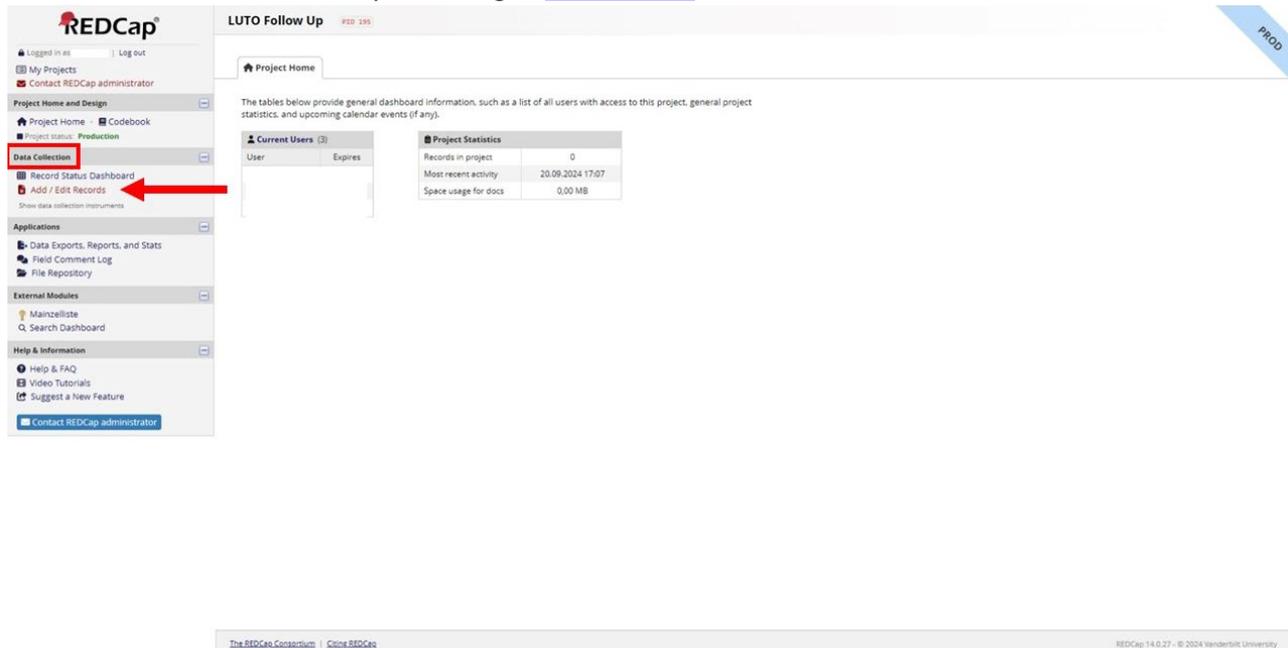
Please select the project you will be entering data for by clicking on the Project Title.

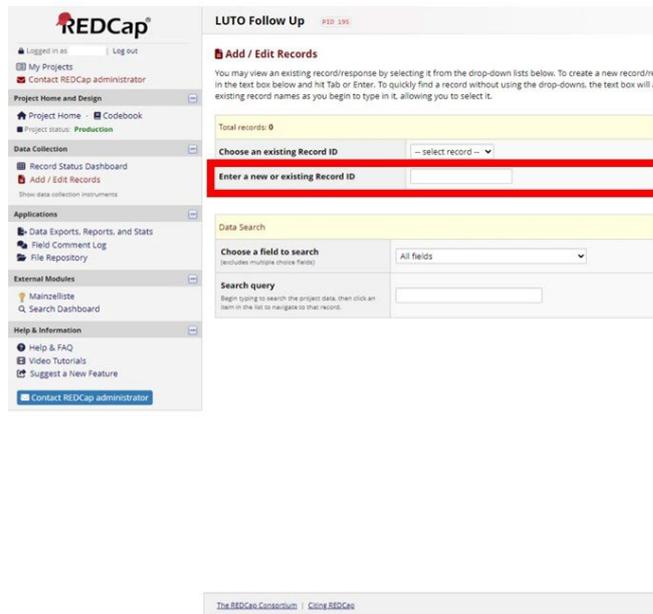
On the left side of your screen you will see the navigation bar.



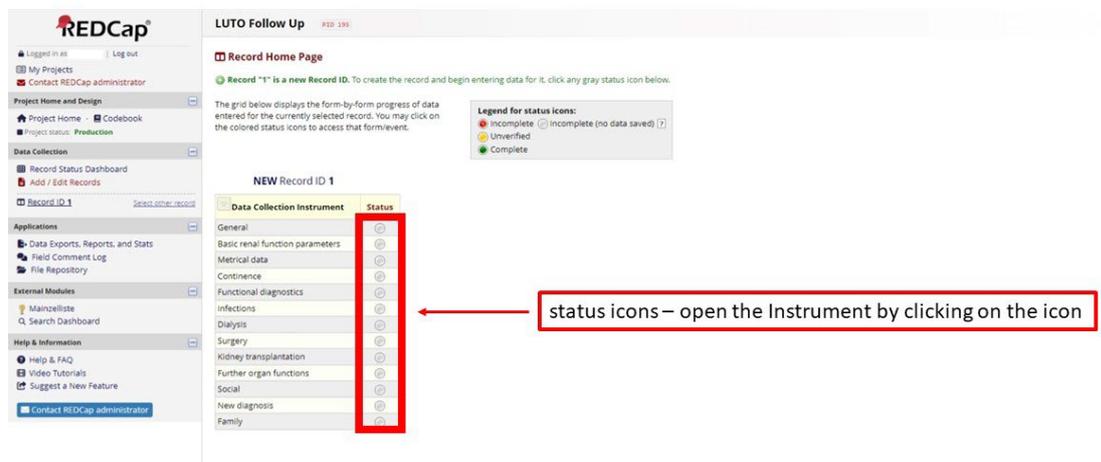
1.3.1 Add new Records

Select *Add/ Edit Records* from the Data collection section to select or enter a participant's Record ID. If you are entering a new set of data, please create the Record ID manually according to [3. Record ID](#).





After entering an ID, you will be directed to the Record Home Page where you will find a grid of the data collection instruments and their data entry status icons which is specific to the Record ID. This grid can be displayed as either a single row (for Pre- and Postnatal) or a grid by time point (for Follow Up).



To open a specific data collection instrument, you can simply click on the status icon.

1.3.2 Edit existing Records

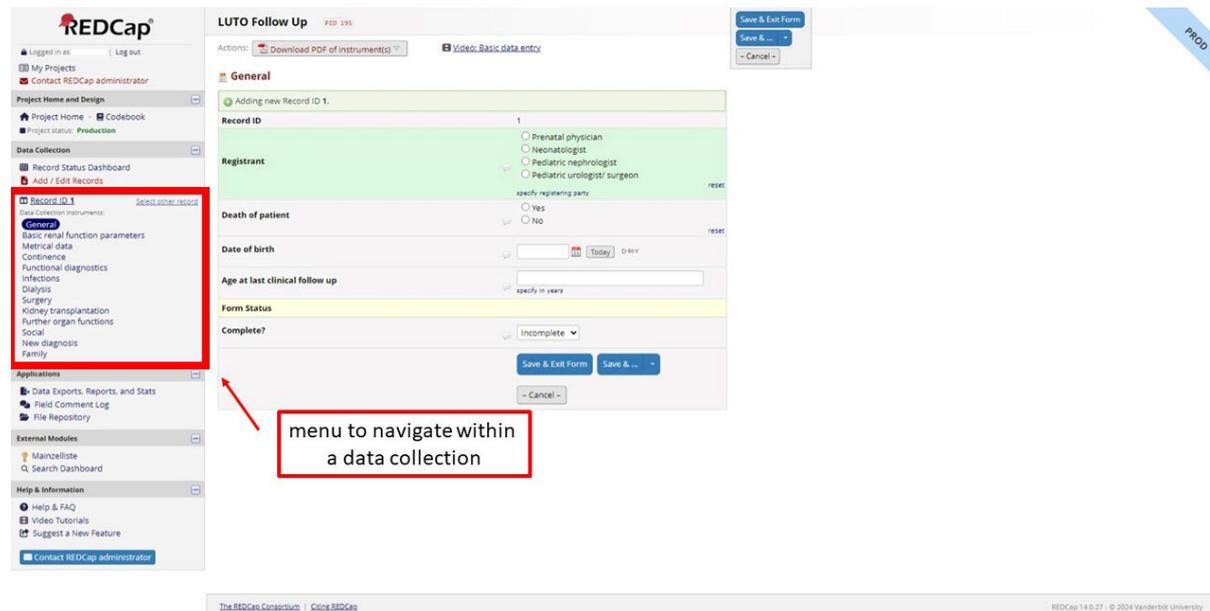
Select *Record Status Dashboard* from the Data Collection section to view all participants inside of your Data Access Group.

On this dashboard you will find an overview of all of the records entered by your location and their respective status sorted by their Record ID. From here on you may choose a record to complete with data or decide on entering a completely new set of data.

Please also note the legend for status icons in the upper right corner of your page.

1.3.3 Navigating within a data collection

When you open a data collection form you will find a menu of instruments on the left side of your screen.



You can use this menu to navigate and switch between instruments during your entry. **However, please make sure to always save the data you entered before switching the instrument to make sure no data is lost in the process.**

1.3.4 Adding to existing Follow Up Records

When entering a patient into the Follow Up survey for the first time, the procedure is exactly the same as when entering a patient into the Prenatal or Postnatal visit. However, after entering the data for the first Follow Up visit, you will find the Record Home Page to be looking as pictured in the following:

In order to add data for the following Follow Up visits you can simply add each Repeating Instrument (e.g. the Metrical data questionnaire) separately. However, due to the option to add each Instrument separately, it is important that you fill out every Instrument when entering a new Follow Up visit. **Please make sure to not forget about one instrument as this would lead to mixing up the Follow Up entries and in the grand scheme mixing up data of different ages. Even if you have no data available for a certain Instrument, it is important that you add the instrument itself, without adding any data and saving it as “Incomplete”.** Additionally, we have enabled the feature to copy data from previous visits, specifically the last visit. When adding a new Repeating Instrument you will find the data you have entered when filling out the Instrument for the last Follow Up visit to be pre-filled in. This way you only have to correct data that has changed within the last year. If the data has not changed, you can simply set the Form Status on the bottom of the page to “Complete” and save the entry.

(4) Saving data

REDCap does not automatically save data.

In order to save the data you entered you either have to use your keyboard’s “Enter” key or you click on the “Save & ...” button in the Form Status section on the bottom of the page.

Please note that using the “Enter” key will also close the data entry screen.

When saving by using the “Save & ...” button, you will have to select the status of the form: incomplete, unverified, or complete. The status icon color on the menu will change to reflect the change in status.

Alternatively, use the “Save & ...” buttons that will always appear in the top right corner of the screen.

The „Save &...“ menu always appears in the top right corner of your screen.

Select the status of your entry: incomplete unverified or complete.

You can also find the „Save &...“ menu At the bottom of every Data Collection Instrument.

It is important to know that REDCap will warn you in case you have not answered required fields or entered data that is out of range, but it can not prevent you from saving your data with these errors.

2. General

(1) *must provide value

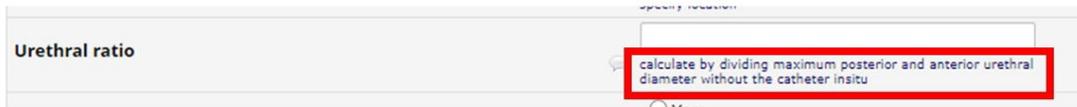
Boxes marked as “must provide value” have to be filled in in order to finish an instrument. If you are not able to provide the needed information, the instrument will be marked as “incomplete”. In this case you can fill in “n/a” instead of the parameter asked for or contact the LUTO support.

If you are not able to provide a required value, a pop-up box will appear to inform you. You can still save your data, even if a “must provide value” is missing.

Please note: In this manual the “must provide values” are marked with **blue highlighter**.

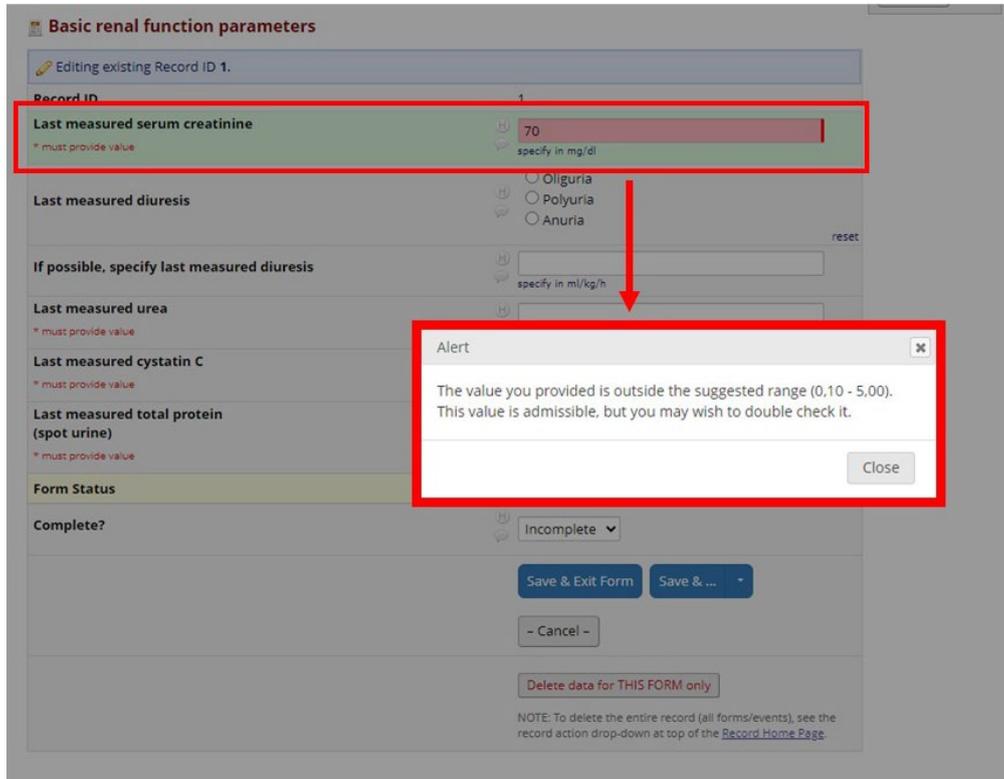
(2) Units to be documented

Each parameter that has to be documented in a certain unit comes with a specification of said unit. If necessary, please convert the unit used in your location to the unit we are looking for.



For certain parameters you will also find instructions on how to calculate the sought-after unit.

(3) Value does not fit the standards



If you document a value that is outside of the standard range, an alert will show up. Please double check your entry. If your entered value is correct, you are still able to save it and complete the instrument.

(4) Reset your entry

When answering a question that uses radio buttons as answer options, you can clear the buttons by clicking “reset” on the bottom right corner of the question field.



3. Record ID

Please always manually create the Record ID according to the following scheme before entering any type of data for a new patient:

Add / Edit Records

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, type a new value in the text box below and hit Tab or Enter. To quickly find a record without using the drop-downs, the text box will auto-populate with existing record names as you begin to type in it, allowing you to select it.

Total records: 1	
Choose an existing Record ID	-- select record --
Enter a new or existing Record ID	<input type="text"/>

Data Search	
Choose a field to search <small>(excludes multiple choice fields)</small>	All fields
Search query <small>Begin typing to search the project data, then click an item in the list to navigate to that record.</small>	<input type="text"/>

LUTO-A0000B

A: describes the type of data collection

A = P for patients that have been included prospectively

A = R for patients that have been included retrospectively

0000: counts up for the number of patients entered from your location

001 = the first patient to be entered into the project by your location

002 = the second patient to be entered into the project by your location

003 = ...

A: stands for the type of survey

A = A for the prenatal survey

A = B for the neonatal survey

A = C for the follow up survey

We use the Record ID to anonymize the data entered through the participating hospitals. In other words, we are not able to trace back the data to a specific patient.

Because of this we kindly ask you to make sure to only enter a patient's data once with a specific Record ID. Especially if there are multiple Data Entry Persons from your location, please make sure there is no duplication of data sets.

Overview of the projects

In the following three chapters you can find an overview of the three projects and a list of every single question you will be asked to answer.

Please note: The “must provide values” are marked with **blue highlighter**.

4. LUTO Pränatal

1) General

1. Record ID

First, create the Record ID manually according to **3. Record ID**.

2. Registrant

Specify registering party. You can only select one.

- Prenatal physician
- Neonatologist
- Pediatric nephrologist
- Pediatric urologist/ surgeon

3. Data collection

Select the applicable type of data collection for the record.

- Prospective
- Retrospective

2) Parent's data at start of pregnancy (baseline data)

1. Fathers's age

Specify father's age in years at the start of pregnancy.

2. Mother's age

Specify mother's age in years at the start of pregnancy.

3. Gravida

Specify number of pregnancies.

4. Para

Specify number of births.

5. Gestational outcome

Specify gestational outcome of further pregnancies. You can select multiple.

Live births

After selecting “Live Births” you will be asked the following follow-up question regarding the live births.

Number of live births

Specify number of live births in a free text box.

Intrauterine fetal deaths (death in utero after WG 24+0)

After selecting “Intrauterine fetal deaths (death in utero after WG 24+0)” you will be asked the following follow-up questions regarding intrauterine fetal deaths.

Number of intrauterine fetal deaths

Specify number of intrauterine fetal deaths in a free text box.

Reason for intrauterine fetal deaths

- Briefly specify reason for intrauterine fetal deaths in a free text box.
- Early miscarriages (in the 1st trimester)
After selecting “Early miscarriages (in the 1st trimester)” you will be asked the following follow-up questions regarding early miscarriages.
 - Number of early miscarriages
Specify number of early miscarriages in a free text box.
 - Reason for early miscarriages
Briefly specify reason for early miscarriages in a free text box.
 - Late miscarriages (in the 2nd trimester)
After selecting “Late miscarriages (in the 2nd trimester)” you will be asked the following follow-up questions regarding late miscarriages.
 - Number of late miscarriages
Specify number of late miscarriages in a free text box.
 - Reason for late miscarriages
Briefly specify reason for late miscarriages in a free text box.
 - Terminations of pregnancy
After selecting “Terminations of pregnancy” you will be asked the following follow-up questions.
 - Number of terminated pregnancies
Specify number of terminated pregnancies in a free text box.
 - Reason for terminated pregnancies
Briefly specify reason for terminated pregnancies in a free text box.
 - Reduction of multiple pregnancy
After selecting “Reduction of multiple pregnancy” you will be asked the following follow-up questions regarding the reduction of multiple pregnancies.
 - Number of reduced multiple pregnancies
Specify number of reduced multiple pregnancies in a free text box.
 - Reason for reduction of multiple pregnancies
Briefly specify reason for reduction of multiple pregnancies in a free text box.
6. Pre-existing maternal conditions
Briefly specify any pre-existing maternal conditions in a free text box.
7. Pre-existing paternal conditions
Briefly specify any pre-existing paternal conditions in a free text box.
8. Medication of mother
Briefly specify medication of mother in a free text box.
9. Any abnormalities of kidneys/ urinary tract in family
Select whether or not there have been any abnormalities of the kidneys/ urinary tract in the family.
- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding any abnormalities of kidneys/ urinary tract in the family.
 - Person concerned
Specify relation to patient in a free text box.
 - Health condition of person concerned

Briefly specify health condition of the person concerned in a free text box.

- No

10. Mother's level of education

Select mother's highest level of education.

- Without degree
- Secondary school diploma
- A-level/ High school diploma
- Completion of recognized vocational training
- University if applied science degree
- Bachelor's
- Diplom/ Magister/Master's/ State Examination
- Doctoral
- Unknown

11. Father's level of education

Select father's highest level of education.

- Without degree
- Secondary school diploma
- A-level/ High school diploma
- Completion of recognized vocational training
- University if applied science degree
- Bachelor's
- Diplom/ Magister/Master's/ State Examination
- Doctoral
- Unknown

3) Diagnosis

1. Time of diagnosis at the registered gynaecologist

Specify week of pregnancy in "week + days" in which the diagnosis was made at the registered gynaecologist.

2. Time of diagnosis in specialised prenatal diagnostics

Specify week of pregnancy in "week + days" in which the diagnosis was made in specialised prenatal diagnostics.

3. Previous diagnostics during pregnancy

Select which diagnostics have been performed during the pregnancy.

- NIPT
- Extended ETS
- Ultrasound examination

After selecting "Ultrasound examination" you will be asked the following follow-up questions.

- Time of ultrasound examination(s)

Select the trimester(s) in which an ultrasound examination was performed.

- 1st trimester
- 2nd trimester
- 3rd trimester

- Depending on which trimester you select, the applicable questions will be shown to you.

1st trimester

Results of first trimester ultrasound examination

- First trimester
Specify which applies to the first trimester.
 - Longitudinal bladder
 - Umbilical cord cysts
- Crown-rump length
Specify crown-rump length in centimeters in a free text box.
- Estimated weight
Select estimated weight.
 - Normal
 - Small gestational age
- **Quantity of amniotic fluid**
Select quantity of amniotic fluid.
 - Normal
 - Oligohydramnios
 - Anhydramnios
- **Bladder diameter**
Specify bladder diameter in millimeters in a free text box.
- Ultrasound examination of the head
Select whether or not an ultrasound examination of the head was performed.
 - Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the ultrasound examination of the head.
 - BPD
Specify biparietal diameter in millimeters.
 - FOD
Specify frontoccipital diameter in millimeters.
 - Neurosonography
Select whether or not the neurosonography was remarkable.
 - ❖ Unremarkable
 - ❖ Remarkable
Briefly specify abnormalities in neurosonography in a free text box.
 - No
- Result of echocardiography
Briefly specify the results of the echocardiography in a free text box.
- Abdomen: torso
Specify the torso measures in millimeters.
- Abdomen: ap
Specify the anterior-posterior measures of the abdomen in millimeters.
- Tubular bones: femur
Specify femur length in millimeters.

2nd trimester

Results of second trimester ultrasound examination

- Second trimester
Specify which applies to the second trimester.
 - Longitudinal bladder
 - Umbilical cord cysts
- Crown-rump length
Specify crown-rump length in centimeters in a free text box.
- Estimated weight
Select estimated weight.
 - Normal
 - Small gestational age
- **Quantity of amniotic fluid**
Select quantity of amniotic fluid.
 - Normal
 - Oligohydramnios
 - Anhydramnios
- **Bladder diameter**
Specify bladder diameter in millimeters in a free text box.
- Ultrasound examination of the head
Select whether or not an ultrasound examination of the head was performed.
 - Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the ultrasound examination of the head.
 - BPD
Specify biparietal diameter in millimeters.
 - FOD
Specify frontocipital diameter in millimeters.
 - Neurosonography
Select whether or not the neurosonography was remarkable.
 - ❖ Unremarkable
 - ❖ Remarkable
Briefly specify abnormalities in neurosonography in a free text box.
 - No
- Result of echocardiography
Briefly specify the results of the echocardiography in a free text box.
- Abdomen: torso
Specify the torso measures in millimeters.
- Abdomen: ap
Specify the anterior-posterior measures of the abdomen in millimeters.
- Tubular bones: femur
Specify femur length in millimeters.

3rd trimester

Results of third trimester ultrasound examination

- Third trimester
Specify which applies to the third trimester.

- Longitudinal bladder
- Umbilical cord cysts
- Crown-rump length
Specify crown-rump length in centimeters in a free text box.
- Estimated weight
Select estimated weight.
 - Normal
 - Small gestational age
- **Quantity of amniotic fluid**
Select quantity of amniotic fluid.
 - Normal
 - Oligohydramnios
 - Anhydramnios
- **Bladder diameter**
Specify bladder diameter in millimeters in a free text box.
- Ultrasound examination of the head
Select whether or not an ultrasound examination of the head was performed.
 - Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the ultrasound examination of the head.
 - BPD
Specify biparietal diameter in millimeters.
 - FOD
Specify frontoccipital diameter in millimeters.
 - Neurosonography
Select whether or not the neurosonography was remarkable.
 - ❖ Unremarkable
 - ❖ Remarkable
Briefly specify abnormalities in neurosonography in a free text box.
 - No
- Result of echocardiography
Briefly specify the results of the echocardiography in a free text box.
- Abdomen: torso
Specify the torso measures in millimeters.
- Abdomen: ap
Specify the anterior-posterior measures of the abdomen in millimeters.
- Tubular bones: femur
Specify femur length in millimeters.

General results of ultrasound examination

- Doppler values
Select trimesters in which doppler values have been measured.
 - 1st trimester
 - First trimester: Ductus venosus
Specify Ductus venosus RI.
 - 2nd trimester

- Second trimester: A. umbilicalis
Specify A. umbilicalis RI.
- Second trimester: A. cerebri media
Specify A. cerebri media RI.
- Second trimester: Ductus venosus
Specify Ductus venosus RI.
- 3rd trimester
 - Third trimester: A. umbilicalis
Specify A. umbilicalis RI.
 - Third trimester: A. cerebri media
Specify A. cerebri media RI.
 - Third trimester: Ductus venosus
Specify Ductus venosus RI.
- No maternal doppler values
- Genital
Select genital. You can only select one.
 - Female
 - Male
 - OtherBriefly specify other genital in a free text box.
- Singular umbilical artery
Select whether or not a single umbilical artery has been observed.
- Dilatation of the renal pelvis
Select whether or not a dilatation of the renal pelvis has been observed and if so, specify side, date and dilatation.
 - No
 - Right side
 - Date of first notice of renal pelvis dilatation
Specify week of gestation in “week + day” in which the dilatation has been observed for the first time.
 - Dilatation on the right side
Specify measurements of the dilatation in anterior-posterior in millimeters.
 - Left side
 - Date of first notice of renal pelvis dilatation
Specify week of gestation in “week + day” in which the dilatation has been observed for the first time.
 - Dilatation on the right side
Specify measurements of the dilatation in anterior-posterior in millimeters.
- Hyperechogenicity of the kidneys
Select whether or not hyperechogenicity of the kidneys has been observed.
- Kidney size
Specify kidney size in anterior-posterior x length x transverse
- Other renal abnormalities
Select which other renal abnormalities have been observed.
 - Cortical cysts
 - Cortical cysts

Select side(s) of cortical cysts. You can select multiple.

- Right
- Left
- Parenchymal cysts
- None
- Megacystis
Select whether or not megacystis was observed.
- Quantity of amniotic fluid
Select the quantity of amniotic fluid.
 - Normal
 - Oligohydramnios
 - Anhydramnios
 - AFI/ single deepest pocket
Specify single deepest pocket in centimeters.

Further diagnosis

1. Other sonographic abnormalities

Select whether or not other sonographic abnormalities have been observed.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding other sonographic abnormalities.
 - Location of sonographic abnormalities
Select the location of sonographic abnormalities.
 - Neurological
Briefly describe sonographic abnormality in a free text box.
 - Heart
Briefly describe sonographic abnormality in a free text box.
 - Abdomen
Briefly describe sonographic abnormality in a free text box.
 - Spine
Briefly describe sonographic abnormality in a free text box.
 - Extremities
Briefly describe sonographic abnormality in a free text box.
 - Other
Briefly describe sonographic abnormality in a free text box.
- No

2. Suspected prenatal diagnosis

Select suspected prenatal diagnosis. You can select multiple.

- PUV
- Urethral atresia
- Urethral stenosis
- MMHIS
- Vesico-ureteral reflux (megacystis-megaureter syndrome)
- Unclear
- Other suspected diagnosis
Briefly specify other suspected diagnosis in a free text box.
- None

- 4) Counselling of the parents
 1. Consultation in prenatal diagnostics
Specify week of pregnancy in “week + days” in which the parents received counselling in prenatal diagnostics.
 2. Consultation in neonatology
Specify week of pregnancy in “week + days” in which the parents received counselling in neonatology.
 3. Consultation in pediatric nephrology
Specify week of pregnancy in “week + days” in which the parents received counselling in pediatric nephrology.
 4. Consultation in pediatric urology
Specify week of pregnancy in “week + days” in which the parents received counselling in pediatric urology.
- 5) Genetic diagnostics
 1. Genetic diagnostics
Select the genetic diagnostics performed during pregnancy.
 - Non-invasive prenatal screening test (NIPT)
 - Material used
Select material used for genetic diagnostics. You can select multiple.
 - Chorionic villi
 - Amniotic fluid
 - Umbilical cord blood
 - Urine
 - NIPT result positive
Select whether or not the result of the NIPT was positive.
 - Yes
 - No
 - Chromosome analysis
 - Material used
Select material used for genetic diagnostics. You can select multiple.
 - Chorionic villi
 - Amniotic fluid
 - Umbilical cord blood
 - Urine
 - Chromosome analysis result positive
Select whether or not the result of the chromosome analysis was positive.
 - Yes
 - No
 - Array CGH
 - Material used
Select material used for genetic diagnostics. You can select multiple.
 - Chorionic villi
 - Amniotic fluid

- Umbilical cord blood
 - Urine
 - Array CGH result positive
Select whether or not the result of the Array CGH was positive.
 - Yes
 - No
- Panel sequencing
 - Material used
Select material used for genetic diagnostics. You can select multiple.
 - Chorionic villi
 - Amniotic fluid
 - Umbilical cord blood
 - Urine
 - Panel sequencing result positive
Select whether or not the result of the panel sequencing was positive.
 - Yes
 - No
- Exome sequencing
 - Material used
Select material used for genetic diagnostics. You can select multiple.
 - Chorionic villi
 - Amniotic fluid
 - Umbilical cord blood
 - Urine
 - Exome sequencing result positive
Select whether or not the result of the exome sequencing was positive.
 - Yes
 - No
- None

6) Fetal urine biochemistry

1. Vesicocentesis

Select whether or not a vesicocentesis was performed.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the vesicocentesis.
 - Number of vesicocentesis
Select the number of performed vesicocentesis.
 - 1
 - 2
 - 3
 - 4
 - 5
 - More than 5
 - Specific value: Calcium
Specify calcium in mmol/l.
 - Specific value: Chloride

- No
 - Specify chloride in mmol/ l.
 - Specific value: Sodium
Specify sodium in mmol/l.
 - Specific value: Osmolarity
Specify osmolarity in mosm/l.
 - Specific value β -2-Microglobulin
Specify β -2-Microglobulin in mg/l.
- 7) Shunt insertion during pregnancy
 - 1. Shunt insertion during pregnancy
 - Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the shunt insertion during pregnancy.

 - **Time of shunt insertion**
Specify time of shunt insertion in “week + days(s)”
 - Type of shunt used
Select the type of shunt used. You can only select one.
 - Rocket
 - Harrison
 - Somatex
 - Intrauterine antibiotic instillation
Select whether or not an intrauterine antibiotic instillation was necessary.
 - Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the intrauterine antibiotic instillation.

 - ❖ Antibiotics used
Briefly specify used antibiotics in a free text box
 - No
 - **Complications**
Select the complications that occurred during the shunt insertion during pregnancy. You can select multiple.
 - No complications
 - Insufficient urine drainage
 - Malposition of the shunt
 - Multiple placements within same intervention (>1)
 - Premature rupture of the bladder
 - Haemorrhage
 - Placental abruption
 - Dislocation of the shunt

After selecting “Dislocation of the shunt” you will be asked the following follow-up questions regarding the dislocation of the shunt.

 - ❖ **Time of dislocation**
Specify time of dislocation in “week + day(s)”.
 - ❖ **Location of dislocation**
Select the location of the dislocation. You can only select one.
 - Foetal

- Maternal
- Amniotic fluid
- Repeated intervention(s)
Briefly describe repeated intervention(s).
- Induction of labour
- Preterm birth
- No

8) Amniotic fluid replenishment

1. Amniotic fluid filling

Select whether or not an amniotic fluid filling was performed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the amniotic fluid filling.

- Number of amniotic fluid fillings

Select number of amniotic fluid fillings.

- 1

After selecting “1” you will be asked the following follow-up questions regarding the single amniotic fluid filling.

- ❖ Time of first amniotic fluid filling
Specify time of first amniotic fluid filling in “week + day(s)”.
- ❖ Intrauterine antibiotic instillation during first amniotic fluid filling
Select whether or not an intrauterine antibiotic instillation during first amniotic filling was necessary.
 - Yes
Briefly specify antibiotics used during first amniotic filling.
 - No
- ❖ Complications during first amniotic fluid filling
Select complications that occurred during first amniotic fluid filling. You can select multiple.
 - No complications
 - Haemorrhage
 - Placental abruption
 - New refilling needed
 - Labour induction
 - Preterm birth

- 2

After selecting “2” you will be asked the same questions as for “1” and additionally the following questions regarding the second amniotic fluid filling.

- ❖ Time of second amniotic fluid filling
Specify time of second amniotic fluid filling in “week + day(s)”.
- ❖ Intrauterine antibiotic instillation during second amniotic fluid filling

Select whether or not an intrauterine antibiotic instillation during second amniotic filling was necessary.

- Yes
Briefly specify antibiotics used during second amniotic filling.
- No

❖ Complications during second amniotic fluid filling

Select complications that occurred during second amniotic fluid filling. You can select multiple.

- No complications
- Haemorrhage
- Placental abruption
- New refilling needed
- Labour induction
- Preterm birth

• 3

After selecting “3” you will be asked the same questions as for “2” and additionally the following questions regarding the third amniotic fluid filling.

❖ Time of third amniotic fluid filling

Specify time of third amniotic fluid filling in “week + day(s)”.

❖ Intrauterine antibiotic instillation during third amniotic fluid filling

Select whether or not an intrauterine antibiotic instillation during third amniotic filling was necessary.

- Yes
Briefly specify antibiotics used during third amniotic filling.
- No

❖ Complications during third amniotic fluid filling

Select complications that occurred during third amniotic fluid filling. You can select multiple.

- No complications
- Haemorrhage
- Placental abruption
- New refilling needed
- Labour induction
- Preterm birth

- No

9) Follow Up depending on the procedure

1. Follow up group

Select the follow up group the patient is in. Depending on the answer you choose you will be directed to the respective data collection instrument.

- Wait and see (without intervention)
- Foetal therapy

9.1) Wait and see (without intervention)

1. Time of ultrasound examination

Select time of ultrasound examination.

- 2nd trimester
- 3rd trimester

2. Ultrasound examination of the head

Select whether or not an ultrasound examination of the head was performed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the ultrasound examination of the head.

- BPD
Specify biparietal diameter in millimetres.
- FOD
Specify frontooccipital diameter in millimetres.

- **Neurosonography**

Select the result of the neurosonography.

- Unremarkable
- Remarkable

Briefly specify any abnormalities in the neurosonography in a free text box.

- No

3. Results of echocardiography

Briefly specify the results of echocardiography in a free text box.

4. Abdomen: transverse

Specify transverse abdomen measures in millimetres.

5. Abdomen: anterior-posterior

Specify anterior-posterior abdomen measures in millimetres.

6. Tubular bones: Femur length

Specify femur length in millimetres.

7. Doppler values

If applicable, select the trimester(s) in which Doppler values have been measured. You can select multiple

- 1st trimester

After selecting “1st trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 1st trimester.

- **Ductus venosus**

Specify RI of Ductus venosus.

- 2nd trimester

After selecting “2nd trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 2nd trimester.

- A. umbilicalis

- Specify RI of A. umbilicalis.
 - A. cerebri media
Specify RI A. cerebri media.
 - **Ductus venosus**
Specify RI of Ductus venosus.
- 3rd trimester
After selecting “3rd trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 3rd trimester.
 - A. umbilicalis
Specify RI of A. umbilicalis.
 - A. cerebri media
Specify RI of A. cerebri media.
 - **Ductus venosus**
Specify RI of Ductus venosus.
- No maternal Doppler values

8. Genital

Select the patient’s genital.

- Female
- Male
- Other

Briefly specify other genital in a free text box.

9. Singular umbilical artery

Select whether or not the patient has a single umbilical artery.

10. Umbilical cord cysts

Select whether or not the patient has umbilical cord cysts.

11. Dilatation of the renal pelvis

Select whether or not the patient shows a dilatation of the renal pelvis and if applicable, select the affected side.

- Left
 - Dilatation on the left side
Specify dilatation in anterior-posterior in millimetres.
- Right
 - Dilatation on the right side
Specify dilatation in anterior-posterior in millimetres.
- None

12. Hyperechogenicity of the kidneys

Select whether or not a hyperechogenicity of the kidneys was observed.

13. Kidney size

Specify kidney size in anterior-posterior x length x diameter in millimeters.

14. Other renal abnormalities

Select other renal abnormalities, if applicable. You can select multiple.

- Cortical cysts

After selecting “Cortical cysts” you will be asked the following follow-up question regarding the cortical cysts.

- Cortical cysts
Select the side on which cortical cysts were observed.
 - Right
 - Left
- Parenchymal cysts
After selecting “Parenchymal cysts” you will be asked the following follow-up question regarding the parenchymal cysts.
 - Parenchymal cysts
Select the side on which parenchymal cysts were observed.
 - Right
 - Left
- None

15. Megacystis

Select whether or not megacystis was observed.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the megacystis.
 - Maximum diameter
Specify maximum diameter in millimetres.
 - Key hole sign
Select whether or not a key hole sign has been observed.
 - Bladder wall thickness
Specify bladder wall thickness in millimetres.
 - Dilatation of the ureters
Select whether or not a dilatation of the ureters was observed.
 - Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the dilatation of the ureters.
 - Location of the dilatation
Select the location of the dilatation.
 - ❖ Left side
 - Width of dilatation in the left side
Specify width of the dilatation on the left side.
 - ❖ Right side
 - Width of dilatation in the right side
Specify width of the dilatation on the right side.
 - No
- No

16. Quantity of amniotic fluid

Select quantity of amniotic fluid. You can select multiple.

- Normal
- Oligohydramnios
- Anhydramnios
- AFI/ single deepest pocket
 - Single deepest pocketSpecify single deepest pocket in centimetres.

17. Estimated weight

Select estimated weight.

- Normal
- Small gestational age
- Large gestational age

Further diagnosis

18. Other sonographic abnormalities

Select whether or not other sonographic values have been observed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the sonographic abnormalities.

 - Sonographic abnormalities

Select the location of the sonographic abnormalities.

 - Neurological
Briefly describe abnormality in a free text box.
 - Heart
Briefly describe abnormality in a free text box.
 - Abdomen
Briefly describe abnormality in a free text box.
 - Spine
Briefly describe abnormality in a free text box.
 - Extremities
Briefly describe abnormality in a free text box.
 - Other
Briefly describe abnormality in a free text box.
- No

9.2) Follow UP after foetal intervention

1. Estimated weight

Select estimated weight.

- Normal
- Small gestational age
- Large gestational age

2. Ultrasound examination of the head

Select whether or not an ultrasound examination of the head was performed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the ultrasound examination of the head.

- BPD
Specify biparietal diameter in millimetres.
- FOD
Specify frontooccipital diameter in millimetres.
- **Neurosonography**
Select the result of the neurosonography.
 - Unremarkable
 - RemarkableBriefly specify any abnormalities in the neurosonography in a free text box.

○ No

3. Abdomen: transverse

Specify transverse abdomen measures in millimetres.

4. Abdomen: anterior-posterior

Specify anterior-posterior abdomen measures in millimetres.

5. Tubular bones: Femur length

Specify femur length in millimetres.

6. Doppler values

If applicable, select the trimester(s) in which Doppler values have been measured. You can select multiple

○ 1st trimester

After selecting “1st trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 1st trimester.

▪ **Ductus venosus**

Specify RI of Ductus venosus.

○ 2nd trimester

After selecting “2nd trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 2nd trimester.

▪ A. umbilicalis

Specify RI of A. umbilicalis.

▪ A. cerebri media

Specify RI A. cerebri media.

▪ **Ductus venosus**

Specify RI of Ductus venosus.

○ 3rd trimester

After selecting “3rd trimester” you will be asked the following follow-up question regarding the Doppler values measured during the 3rd trimester.

▪ A. umbilicalis

Specify RI of A. umbilicalis.

▪ A. cerebri media

Specify RI of A. cerebri media.

▪ **Ductus venosus**

Specify RI of Ductus venosus.

- No maternal Doppler values

7. Genital

Select the patient's genital.

- Female
- Male
- Other

Briefly specify other genital in a free text box.

8. Singular umbilical artery

Select whether or not the patient has a single umbilical artery.

9. Umbilical cord cysts

Select whether or not the patient has umbilical cord cysts.

10. Dilatation of the renal pelvis

Select whether or not the patient shows a dilatation of the renal pelvis and if applicable, select the affected side.

- Left
 - Dilatation on the left side
Specify dilatation in anterior-posterior in millimetres.
- Right
 - Dilatation on the right side
Specify dilatation in anterior-posterior in millimetres.
- None

11. Hyperechogenicity of the kidneys

Select whether or not a hyperechogenicity of the kidneys was observed.

12. Kidney size

Specify kidney size in anterior-posterior x length x diameter in millimeters.

13. Other renal abnormalities

Select other renal abnormalities, if applicable. You can select multiple.

- Cortical cysts

After selecting "Cortical cysts" you will be asked the following follow-up question regarding the cortical cysts.

 - Cortical cysts
Select the side on which cortical cysts were observed.
 - Right
 - Left
- Parenchymal cysts

After selecting "Parenchymal cysts" you will be asked the following follow-up question regarding the parenchymal cysts.

 - Parenchymal cysts
Select the side on which parenchymal cysts were observed.
 - Right
 - Left

- None

14. Megacystis

Select whether or not megacystis was observed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the megacystis.

- Maximum diameter
Specify maximum diameter in millimetres.

- Key hole sign
Select whether or not a key hole sign has been observed.

- Bladder wall thickness
Specify bladder wall thickness in millimetres.

- Dilatation of the ureters
Select whether or not a dilatation of the ureters was observed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the dilatation of the ureters.

- Location of the dilatation

Select the location of the dilatation.

- ❖ Left side

- Width of dilatation in the left side
Specify width of the dilatation on the left side.

- ❖ Right side

- Width of dilatation in the right side
Specify width of the dilatation on the right side.

- No

- No

15. Quantity of amniotic fluid

Select quantity of amniotic fluid. You can select multiple.

- Normal
- Oligohydramnios
- Anhydramnios
- AFI/ single deepest pocket
 - Single deepest pocket
Specify single deepest pocket in centimetres.

16. Shunt position correct

Select whether or not the shunt position was correct.

- Yes
- No

After selecting “No” you will be asked the following follow-up questions regarding the shunt position.

- Shunt dislocation
Select location the shunt was dislocated to. You can only select one.
 - Intraabdominal
 - Intraamniacal
 - Myometrial
 - Intravesical
- Renewed intervention
Select whether or not a renewed shunt insertion was performed.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the renewed shunt insertion.
 - ❖ Time of renewed shunt insertion
Specify time of renewed shunt insertion in “week + day(s)”.
 - ❖ Type of shunt used
Select the type of shunt used. You can only select one.
 - Rocket
 - Harrison
 - Somatex
 - ❖ Direct complications during intervention
Select whether or not direct complications occurred during the procedure and if applicable, select complications.
 - None
 - Technical
 - Maternal
 - Foetal
 - No

Further diagnosis

17. Other sonographic abnormalities

Select whether or not other sonographic values have been observed.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the sonographic abnormalities.
 - Sonographic abnormalities
Select the location of the sonographic abnormalities.
 - Neurological
Briefly describe abnormality in a free text box.
 - Heart
Briefly describe abnormality in a free text box.
 - Abdomen
Briefly describe abnormality in a free text box.
 - Spine
Briefly describe abnormality in a free text box.
 - Extremities
Briefly describe abnormality in a free text box.

- Other
Briefly describe abnormality in a free text box.
- No

10) Further Follow Up for both groups

1. Premature rupture of membranes

Select whether or not there was a premature rupture of membranes.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the premature rupture of membranes.
 - Time of premature rupture of bladder
Specify age in which the premature rupture of membranes occurred in “week + day”.
 - Tocolysis
Select the tocolysis that was given.
 - Nifedipine
 - Indomethacin
 - Atosiban
 - Fenoterol
 - Other
Briefly specify other tocolysis in a free text box.
 - Antenatal corticosteroids
Select whether or not antenatal corticosteroids were given or not.
 - Triple I
Select whether or not Triple I was diagnosed.
- No

2. Cervical insufficiency (< 15 mm)

Select whether or not a cervical insufficiency was diagnosed.

3. Further Follow up

Select whether or not preterm labour occurred.

- Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the preterm labour.
 - Time of occurrence of preterm labour
Specify time of occurrence of preterm labour in “week + day(s)”.
 - Tocolysis
Select the tocolysis that was given.
 - Nifedipine
 - Indomethacin
 - Atosiban
 - Fenoterol
 - Other
Briefly specify other tocolysis in a free text box.
 - Antenatal corticosteroids
Select whether antenatal corticosteroids were given.
- No

4. Premature placental abruption
Select whether or not a premature placental abruption occurred.
5. Other
Briefly specify any important information regarding that has not been queried up until this point.

11) Birth

1. Week of gestation

Specify gestational week of birth in “week + days”.

2. Spontaneous labour
Select whether or not the labour started spontaneously.

3. Induction
Select whether or not the labour was induced.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the induction.

- Reason for induction

Select the reason for induction. You can select multiple.

- ❖ Infection
 - ❖ Rupture of membranes
 - ❖ Severe growth restriction
 - ❖ Pathological Doppler
 - ❖ Gestational age
 - ❖ Intrauterine foetal death (IUFT)
 - ❖ Maternal indications
 - ❖ Other reasons

Briefly specify other reasons for induction in a free text box.

- No

4. Mode of labour

Select mode of labour.

- Spontaneous
 - Urgent caesarean section
Specify reason for urgent caesarean section in a free text box.
 - Immediate caesarean section
Specify reason for immediate caesarean section in a free text box.
 - Vaginal surgery
Specify reason for vaginal surgery in a free text box.
5. APGAR after 1 minute.
Specify APGAR score after one minute according to Dr. Virginia Apgar (1952).
 6. APGAR after 5 minutes

Specify APGAR score after five minutes according to Dr. Virginia Apgar (1952).

7. APGAR after 10 minutes

Specify APGAR score after ten minutes according to Dr. Virginia Apgar (1952).

8. Umbilical cord pHa

Specify umbilical cord artery pH.

9. Umbilical cord pHv

Specify umbilical cord venous pH.

10. Umbilical cord BE

Specify umbilical cord base excess.

11. Birth weight

Specify birth weight in grams.

12. Head circumference

Specify head circumference in centimeters.

13. Body length

Specify body length in centimeters.

14. NICU transfer

Select whether or not the patient was transferred to the NICU.

- Yes
- No

15. Maternal postpartum complications

Select applicable maternal postpartum complications. You can select multiple.

- Uterus atony
- Infection
- Transfer to ICU
- Other

Briefly specify other postpartum complications in a free text box.

5. LUTO Postnatal

1) General

1. Record ID

First, create the Record ID manually according to [3. Record ID](#).

2. Registrant

Specify registering party. You can only select one.

- Prenatal physician
- Neonatologist
- Pediatric nephrologist
- Pediatric urologist/ surgeon

3. Data collection

Select the applicable type of data collection for the record.

- Prospective
- Retrospective

2) Birth and primary care

Birth parameters

1. Week of gestation

Specify week of gestation in “week + day(s)”.

2. Birth weight

Specify the weight at birth in grams.

3. Mode of labour

Select the mode of labour. You can only select one.

- Spontaneous
- Cesarean section
- Urgent cesarean section
 - Additionally, briefly specify reason for urgent cesarean section.
- Emergency cesarean section
 - Additionally, briefly specify reason for emergency cesarean section.
- Vacuum extraction
 - Additionally, briefly specify reason for urgent cesarean section.
- Forceps delivery
 - Additionally, briefly specify reason for urgent cesarean section.

Primary care

4. APGAR after 1 minute

Specify APGAR score after one minute according to Dr. Virginia Apgar (1952).

5. APGAR after 5 minutes

Specify APGAR score after 5 minutes according to Dr. Virginia Apgar (1952).

6. APGAR after 10 minutes

Specify APGAR score after 10 minutes according to Dr. Virginia Apgar (1952).

7. Umbilical cord pH
Specify umbilical cord pH.

8. Respiratory support

Select respiratory support obtained right after birth. You can only select one.

- Resuscitator
- CPAP (= continuous positive airway pressure)
- Intubation
- None

3) Postnatal Diagnosis

VCUG

1. VCUG performed (= voiding cystourethrography) performed

Select whether or not a VCUG was performed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the VCUG:

- Date of VCUG

Specify day of life on which the VCUG was performed.

- Urethra

Select urethra-related diagnosis. You can select multiple.

- PUV (= posterior urethral valves)
- Urethral atresia
- Urethral stenosis
- Double stenotic urethra
- None
- Other

After selecting “Other” you will be asked to briefly specify other urethra-related diagnosis in a free text box.

- Thickening of bladder wall

Select whether or not a thickening of the bladder wall was noticed or.

- Yes
- No

- Trabeculation of bladder wall

Select whether or not a trabeculation of the bladder wall was noticed.

- Yes
- No

- Bladder capacity

Select which bladder capacity was determined. You can only select one.

- Hypocapacitive
- Normal
- Hypercapacitive

Calculate bladder capacity according to this formula:

Bladder capacity (ml) = age (years) + 1 x 30 ml

- **Right ureter**

Select diagnosis regarding the right ureter. You can select multiple.

- Reflux

After selecting “Reflux”, you will be asked to **specify the degree of reflux** ranging from I to V according to the following scheme:

Grade I: reflux into a non-dilated ureter.

Grade II: reflux into the renal pelvis without dilatation.

Grade III: reflux into the renal pelvis, moderate dilatation of the upper tract, and minimal blunting of the calyces.

Grade IV: reflux with significant dilatation of the upper tract, moderate ureteral kinking, and blunting of the calyces with preserved papillary impressions.

Grade V: reflux with gross dilatation of the upper tract, ureteral tortuosity, and loss of papillary impressions.

*Vesicoureteral Reflux: Classification, Diagnosis, and Treatment (urology-textbook.com)
[12.08.2024]*

- Megaureter
- Ureterocele
- No abnormalities
- Other

After selecting “Other” you will be asked to briefly specify abnormalities in a free text box.

- **Left ureter**

Select diagnosis regarding the left ureter. You can select multiple.

- Reflux

After selecting “Reflux”, you will be asked to **specify the degree of reflux** ranging from I to V according to the scheme from above.

- Megaureter
- Ureterocele
- No abnormalities
- Other

After selecting “Other” you will be asked to briefly specify abnormalities in a free text box.

- No

2. Renal sonography performed

Select whether or not a renal sonography was performed.

- Yes

After selecting “Yes” you will be asked the following follow-up questions regarding the renal sonography:

- Date of renal sonography
Specify the day of life on which the renal sonography was performed

Renal sonography: right kidney

- Size
Specify kidney size in length x width x thickness in centimeters.

- Volume
Specify kidney volume in milliliters.
- Width of the renal pelvis
Specify width of the renal pelvis in centimeters.
- Cysts
Select whether or not renal cysts have been detected.
 - Yes
After selecting “Yes” you will be asked the following follow-up questions regarding the cysts that were detected during the renal sonography:
 - Number of cysts
Select number detected of cysts.
 - 1
 - < 10
 - > 10
 - Size of cysts
Select size range of detected cysts.
 - Small cystic
 - Large cystic
 - Localization of cysts
Select localization of detected cysts.
 - Cortical
 - Medullary
 - Cortical-medullary junction
 - Ubiquitous
 - No
- Faded medullary cortical differentiation
Select whether or not a faded medullary cortical differentiation has been detected.
 - Yes
 - No
- Dysplasia
Select whether or not a renal dysplasia has been detected.
 - Yes
 - No

Renal sonography: left kidney

- Size
Specify kidney size in length x width x thickness in centimeters.
- Volume
Specify kidney volume in milliliters.
- Width of the renal pelvis
Specify width of the renal pelvis in centimeters.
- Cysts
Select whether or renal cysts have been detected.
 - Yes

After choosing “Yes” you will be asked the following follow-up questions regarding the cysts that were detected during the renal sonography:

- Number of cysts
Select number detected of cysts.
 - 1
 - < 10
 - > 10
- Size of cysts
Select size range of detected cysts.
 - Small cystic
 - Large cystic
- Localization of cysts
Select localization of detected cysts.
 - Cortical
 - Medullary
 - Cortical-medullary junction
 - Ubiquitous

- No

- **Faded medullary cortical differentiation**

Select whether or not a faded medullary cortical differentiation has been detected.

- Yes
- No

- **Dysplasia**

Select whether or not a renal dysplasia has been detected.

- Yes
- No

Other malformations (regarding both kidneys)

- **Other malformations**

Select which other malformations have been detected. You can select multiple.

- None
- Double kidney system
After selecting “Double kidney system” you will be asked to **select the respective side**. You can select multiple.
 - Right side
 - Left side
- Single kidney
After selecting “Single kidney” you will be asked to **select the respective side**. You can select multiple.
 - Right side
 - Left side
- Horseshoe kidney
- Pelvic kidney

After selecting “Pelvic kidney” you will be asked to **select the respective side**. You can select multiple.

- Right side
- Left side

4) Urinary drainage/ passage

In this section the urinary drainage is to be documented on 2 dates: the 7th day of life and the day of discharge.

7th day of life

1. Time of establishment

Specify day of life on which urinary drainage was established.

2. Urinary drainage/ passage via

Select the localization of the urinary drainage. You can only select one.

- Urethra
- Transurethral shunt
- Suprapubic catheter
- Cystofix
- Inlaying vesico-amnial shunt

After selecting “Inlaying vesico-amnial shunt” you will be asked to select the type of shunt. You can only select one.

- Suprapubic catheter
- Mono-J
- Other

After selecting “Other” you will be asked to briefly specify the type of shunt in a free text box.

On date of discharge

3. Time of establishment

Specify day of life on which urinary drainage used on the day of discharge was established.

4. Urinary drainage/ passage via

Select the localization of the urinary drainage used on the day of discharge. You can only select one.

- Urethra
- Transurethral shunt
- Suprapubic catheter
- Cystofix
- Inlaying vesico-amnial shunt

After selecting “Inlaying vesico-amnial shunt” you will be asked to select the type of shunt. You can only select one.

- Suprapubic catheter
- Mono-J
- Other

After selecting “other” you will be asked to briefly specify the type of shunt in a free text box.

5) Further diagnosis

1. Further diagnosis

Select the area of further diagnoses. You can select multiple.

○ Head

After selecting “Head” you will be asked to further specify the area or choose a diagnosis.

● CNS

After selecting “CNS” you will be able to select multiple out of the following diagnoses.

- Encephalocele
- Occult dysraphia
- Midline defect
- Dandy-Walker-Syndrome
- Joubert (“Molar Tooth”)
- Neurocutaneous syndrome
- Schizencephaly
- Heterotopy
- Lissencephaly
- Polymicrogyria
- Hydrocephalus
- Spina bifida
- Hemorrhage (please specify under “Neonatalogical aspects”)
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the CNS on a free text box.

● Ears

After selecting “Ears” you will be able to select multiple out of the following diagnoses

- Auricle dysplasia degree I
- Auricle dysplasia degree II
- Auricle dysplasia degree III
- Microtia
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the ears in a free text box.

- Cleft lip and palate
- Pierre Robin Sequence
- Choanal atresia
- Microcephaly
- Macrocephaly
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the head in a free text box.

○ Thorax

After selecting “Thorax” you will be able to select multiple out of the following areas.

- Lungs

After selecting “Lungs” you will be able to select multiple out of the following diagnoses.

- Lung sequester (BPS)
- CPAM/ CCAM
- Congenital lobar emphysema
- Bronchogenic cyst
- Pulmonary hypoplasia
- Pulmonary agenesis
- Pulmonary aplasia
- Congenital pulmonary lymphangiectasia
- Tracheomalacia
- Bronchopulmonary dysplasia
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the lungs in a free text box.

- Heart

After selecting “Heart” you will be able to select multiple out of the following diagnoses.

- Persistent Ductus Arteriosus
- Persistent Foramen Ovale
- Transposition of the major arteries
- Aortic coarctation
- Aortic valve stenosis
- Pulmonary valve stenosis
- Atrial septum defect
- Hypoplastic left heart syndrom
- Fallot-Tetralogy
- Ventricular septum defect
- Tricuspid atresia
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the heart in a free text box.

- Esophagus

After selecting “Esophagus” you will be able to select multiple out of the following diagnoses.

- Esophagus atresia
- Congenital esophago-tracheal fistula (H-/N-fistula)
- Laryngo-tracheal-esophageal cleft
- Congenital esophagus stenosis
- Esophageal diverticulum
- Esophageal duplication
- Other

After selecting “Other” you will be asked to briefly specify the diagnosis regarding the esophagus in a free text box.

- Abdomen
 - After selecting “Abdomen” you will be able to select multiple out of the following diagnoses and localizations.
 - Prune Belly
 - Bile duct atresia
 - Diaphragmatic hernia
 - Intestine
 - After selecting “Intestine” you will be able to select multiple out of the following diagnoses.
 - Intestinal obstruction
 - Omphalocele
 - Gastroschisis
 - Small intestine atresia
 - Duodenal atresia
 - Hirschsprung's disease
 - Other
 - After selecting “Other” you will be asked to briefly specify the diagnosis regarding the intestine in a free text box.
 - Anorectum
 - After selecting “Anorectum” you will be able to select multiple out of the following diagnoses.
 - Anal atresia
 - Fistula
 - Ectopic anus
 - Cloacal malformation
 - Other
 - After selecting “Other” you will be asked to briefly specify the diagnosis regarding the anorectum in a free text box.
 - Other
 - After selecting “other” you will be asked to briefly specify the diagnosis regarding the abdomen in a free text box.
- Genital
 - After selecting “Genital” you will be able to select one out of the following specifications.
 - Female
 - After selecting “Female” you will be able to select multiple out of the following diagnoses.
 - Vaginal agenesis
 - Hymenal atresia
 - Cloacal malformation
 - Megalourethra
 - Other
 - After selecting “Other” you will be asked to briefly specify the diagnosis regarding the female genital in a free text box.
 - Male
 - After selecting “Male” you will be able to select multiple out of the following diagnoses.
 - Cryptorchism

- Micropenis
- Hypospadias
- Phimosis
- Hydrocele
- Epispadia
- Penoscrotal transposition
- Megalourethra
- Other
After selecting “Other” you will be asked to briefly specify the diagnosis regarding the male genital in a free text box.
- Other
After selecting “Other” you will be asked to briefly specify the diagnosis regarding the other location in a free text box.
- Extremities
After selecting “Extremities” you will be able to select multiple out of the 2 localizations.
 - Upper limb
After selecting “Upper limb” you will be able to select multiple out of the following diagnoses.
 - Polydactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Syndactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Oligodactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Amelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Peromelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Phocomelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Ectromelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
 - Radial aplasia
 - Other
After selecting “Other” you will be asked to briefly specify the diagnosis regarding the upper limb in a free text box.
 - Lower limb
After selecting “Lower limb” you will be able to select multiple out of the following diagnoses.

- Femur defect
- Fibular hemimelia
- Amelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Peromelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Phocomelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Ectromelia
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Polydactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Syndactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Oligodactyly
After selecting this diagnosis, you will be asked to briefly describe the abnormality in a free text box.
- Other
After selecting “Other” you will be asked to briefly specify the diagnosis regarding the lower limb in a free text box.

6) Neonatological aspects

1. Treatment on NICU

Select whether or not a treatment on the NICU was performed.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the treatment on the NICU.

- Duration of treatment on NICU
Specify the duration of the treatment on the NICU in days.
- Intubation performed
Select whether or not an intubation was performed.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the intubation.
 - Time of intubation
Specify day of life on which intubation was performed.
 - No
- Invasive respiratory support
Select whether or not invasive respiratory support was performed
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the invasive respiratory support.

- Duration of invasive respiratory support
Specify duration of invasive respiratory support in days.
- ECMO treatment
Select whether or not ECMO treatment was performed.
 - ❖ Yes
After selecting “Yes” you will be asked to answer the following follow-up question regarding the ECMO treatment.
 - Duration of ECMO treatment
Specify duration of ECMO treatment in days.
 - ❖ No
 - No
- Non-invasive respiratory support
Select whether or not non-invasive respiratory support was performed.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the non-invasive respiratory support.
 - Duration of non-invasive respiratory support
Specify duration of non-invasive respiratory support in days.
 - No
- Catecholamine therapy performed
Select whether or not a catecholamine therapy was performed.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the catecholamine therapy.
 - Duration of Catecholamine therapy.
Specify duration of catecholamine therapy in days.
 - No
- Bronchopulmonary dysplasia
Select whether or not bronchopulmonary dysplasia according to Walsh et al. (2004) was diagnosed.
Bronchopulmonary dysplasia according to Walsh et al. (2004): premature infants in need of additional oxygen at 36 weeks PMA, oxygen is being withdrawn until infant reaches minimal room air levels, if SpO₂ reaches < 90% for more than 30 minutes during test.
 - Yes
 - No
- CRIB-Score
Specify Clinical Risk Index for Babies according to The International Neonatal Network (1993).
- Complications
Select any complications that occurred during the treatment on the NICU. You can select multiple.
 - IVH (Intraventricular hemorrhage)

After selecting “IVH” you will be asked to answer the following follow-up questions regarding intraventricular hemorrhage.

- IVH degree

Select IVH degree according to Papile et al. (1978)

Grade I – hemorrhage limited to Germinal matrix

Grade II – IVH without ventricular dilatation

Grade III - IVH with ventricular dilatation occupying > 50% of the ventricle

Grade IV – IVH with intraparenchymal hemorrhage

- NEC/ FIP (necrotizing enterocolitis/ focal intestinal perforation)

After selecting “NEC/ FIP” you will be asked to answer the following follow-up questions regarding necrotizing enterocolitis/ focal intestinal perforation.

- Surgery needed

Select whether or not a surgery was needed.

❖ Yes

❖ No

- Infection (inflammatory signs increased)
- Sepsis (microbiologically verified)
- Pneumothorax
- AKI (Acute Kidney Injury)

After selecting “AKI” you will be asked to answer the following follow-up questions regarding the acute kidney injury.

- AKI degree

Select AKI degree.

- Dialysis (specify under "Date of discharge")
- Surgery to remove vesicoamniotic shunt

After selecting “Surgery to remove vesicoamniotic shunt” you will be asked to answer the following follow-up questions regarding the surgery to remove the vesicoamniotic shunt.

- Date of surgery

Specify day of life on which the surgery was performed.

- Complications

Briefly describe any complications that occurred during the surgery in a free text box.

- Visible skin lesions

Select or not whether visible skin lesions occurred.

❖ Yes

❖ No

- Dislocation of shunt

Select whether or not the shunt was dislocated.

❖ Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the dislocation of the shunt.

- Dislocation where to

Specify briefly where the shunt was dislocated to.

❖ No

○ No

7) Course of kidney function

1. Serum creatinine on day 3

Specify serum creatinine on third day of life in milligrams/ deciliter.

2. Diuresis on day 3

Specify diuresis in third day of life in milliliters/ kilograms/ hours.

3. Serum creatinine on day 7

Specify serum creatinine on seventh day of life in milligrams/ deciliter.

4. Diuresis on day 7

Specify diuresis in seventh day of life in milliliters/ kilograms/ hours.

5. Day of discharge

Specify day of life on which the patient was discharged.

6. Serum creatinine on day of discharge

Specify serum creatinine on day of discharge in milligrams/ deciliter.

7. Diuresis on day of discharge

Select applicable diuresis on day of discharge. You can only select one.

- Anuria
- Normal diuresis
- Oliguria

8. Cystatin c on date of discharge

Specify cystatin c on day of discharge in milligrams/ deciliter.

9. Total protein on date of discharge

Specify total protein on day of discharge in milligrams/ grams of creatinine. If possible, use urine status of spontaneous urine.

8) Date of discharge

1. Age on date of discharge

Specify age in days on date of discharge.

2. Body weight on date of discharge

Specify body weight in grams on date of discharge.

3. Dialysis treatment during hospitalization

Select whether or not dialysis treatment was performed during hospitalization.

- Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the dialysis treatment during hospitalization.



- Start of dialysis treatment
Specify day of life on which dialysis treatment first started.
 - Duration of dialysis treatment
Specify duration of dialysis treatment in days.
 - Type of dialysis
Select the type of dialysis used for dialysis treatment. You can select multiple.
 - PD (peritoneal dialysis)
 - HD (hemodialysis)
 - CVVH (continuous veno-venous hemodialysis)
 - No
4. Dialysis treatment on date of discharge
Select whether or not dialysis treatment was performed on date of discharge.

6.LUTO Follow Up

1) General

1. Record ID

First, please create the Record ID manually according to [3. Record ID](#).

2. Registrant

Specify registering party. You can only select one.

- Prenatal physician
- Neonatologist
- Pediatric nephrologist
- Pediatric urologist/ surgeon

3. Data collection

Select the applicable type of data collection for the record.

- Prospective
- Retrospective

4. Death of patient

Select whether or not the patient died since the last LUTO Follow Up entry.

- Yes
 - After selecting “Yes” you will be asked to answer the following follow-up questions regarding the death of the patient.
 - Age at death
 - Specify age in years at time of death.
 - Cause of death
 - Select cause of death. You can only select one.
 - Cardiorespiratory
 - Dialysis-associated
 - Infectiologic
 - Other cause of death, not associated with primary disease
- No

5. Date of birth

Specify the patient’s date of birth.

6. Age at last clinical visit

Specify the age of the patient in years at the last clinical visit in your hospital.

2) Basic renal function parameters

1. Last measured serum creatinine

Specify last measured serum creatinine in milligrams/ deciliter.

2. Last measured diuresis

Select applicable diuresis. You can only select one.

- Anuria
- Normal diuresis
- Oliguria

3. If possible, specify last measured diuresis
Specify last measured diuresis in milliliters/ kilograms/ hours.

4. **Last measured urea**

Specify last measured urea in milligrams/ deciliters.

5. **Last measured cystatin c**

If available, specify last measured cystatin c in milligrams/ liter.

6. **Last measured total protein (spot urine)**

Specify last measured total protein in milligrams/ grams of creatinine. If possible, use urine status of spontaneous urine.

- 3) Metrical data

1. **Height**

Specify body height in centimeters.

2. **Weight**

Specify body weight in kilograms.

3. **Blood pressure**

Specify blood pressure in systolic/ diastolic mmHg. Please provide a value that is representative for the patient.

4. Tanner stages

Specify Tanner stages according to James M. Tanner (1969).

- 4) Continence

Urine continence

1. Continence during the day

Select whether or not patient is continent for urine during the day.

- Yes
- No

After selecting “No” you will be asked to answer the following follow-up questions regarding urination during the day.

- Urination tools
Select the tools used for urination. You can select multiple.
 - Cystofix
 - Stoma
 - Diaper
- Frequency of uncontrolled wetting
Select frequency of uncontrolled wetting. You can only select one.
 - Daily
 - Weekly
 - Occasionally

2. Continence during the night

Select whether patient is continent for urine during the night.

- Yes
- No

After selecting “No” you will be asked to answer the following follow-up questions regarding urination during the night.

- Urination tools

Select the tools used for urination. You can select multiple.

- Cystofix
- Stoma
- Diaper

- Frequency of uncontrolled wetting

Select frequency of uncontrolled wetting. You can only select one.

- Daily
- Weekly
- Occasionally

Stool continence

3. Stool continence

Select whether patient is continent for stool.

- Yes
- No

After selecting “No” you will be asked to answer the following follow-up questions regarding stool incontinence.

- Reason for stool incontinence

Select reason for stool incontinence. You can only select one.

- Constipation with overflow
- Other

Briefly specify other reason for stool incontinence in a free text box.

5) Functional diagnostics

1. Last functional diagnostics

Select functional diagnostics that have been performed since the last Follow Up entry. You can select multiple.

- MAG3 scintiscan

After selecting “MAG2 scintiscan” you will be asked to answer the following follow-up questions regarding the last MAG3 scintiscan.

- Date

Specify month and year of the last MAG3 scintiscan.

- Urodynamically relevant drainage obstacle

Select whether any urodynamically relevant drainage obstacles were found and if so, select the applicable side.

- Right

- Functional proportionality on the right side
Specify functional proportionality on the right side in %.

- Left

- Functional proportionality on the left side

Specify functional proportionality on the left side in %.

- None
- DMSA scintiscan
After selecting “DMSA scintiscan” you will be asked to answer the following follow-up questions regarding the last DMSA scintiscan.
 - Date
Specify month and year of the last DMSA scintiscan.
 - Functional proportionality on the right side
Specify functional proportionality on the right side in %.
 - Functional proportionality on the left side
Specify functional proportionality on the left side in %.
 - Kidney scars
Select whether kidney scars have been found and if so, select the applicable side.
 - Right side
 - Left side
 - None
- Voiding cystourethrography (ger: MCU)
After selecting “Voiding cystourethrography” you will be asked to answer the following follow-up questions regarding the last voiding cystourethrography.
 - Date
Specify month and year of the last voiding cystourethrography.
 - Vesico-ureteral reflux
Select whether vesico-ureteral reflux was diagnosed and if so, select the applicable side.
 - Right side
After selecting “Right side” you will be asked to answer the following follow-up questions regarding vesico-ureteral reflux on the right side.
 - Degree of reflux on the right side
Select degree of reflux on the right side.
 - Left side
After selecting “Left side” you will be asked to answer the following follow-up questions regarding vesico-ureteral reflux on the left side.
 - Degree of reflux on the left side
Select degree of reflux on the left side.
 - None
 - Urethral ratio
Calculate urethral ratio by dividing maximum posterior and anterior urethral diameter without the catheter insitu.
 - Visible constriction of urethra
Select whether or not a visible constriction of the urethra was observed.
 - Yes
 - No
- Voiding urosonography (ger: MUS)
After selecting “Voiding urosonography” you will be asked to answer the following follow-up questions regarding the last voiding urosonography.

- Date
Specify month and year of the last voiding urosonography.
- Vesico-ureteral reflux
Select whether vesico-ureteral reflux was diagnosed and if so, select the applicable side.
 - Right side
After selecting “Right side” you will be asked to answer the following follow-up questions regarding vesico-ureteral reflux on the right side.
 - Degree of reflux on the right side
Select degree of reflux on the right side.
 - Left side
After selecting “Left side” you will be asked to answer the following follow-up questions regarding vesico-ureteral reflux on the left side.
 - Degree of reflux on the left side
Select degree of reflux on the left side.
 - None
- Urodynamics
After selecting “Urodynamics” you will be asked to answer the following follow-up questions regarding the last voiding urodynamics.
 - Date
Specify month and year of the last urodynamics.
 - Bladder capacity
Specify bladder capacity in milliliters.
 - Residual urine
Specify residual urine in milliliters.
 - Miction pressure
Specify miction pressure in centimeters H₂O.
 - Detrusor sphincter dyssynergy
Select whether or not a detrusor sphincter dyssynergy was observed.
 - Yes
 - No
 - Intravesical rest pressure for 50 ml
Specify intravesical rest pressure for 50 ml in centimeters H₂O.
 - Intravesical rest pressure for 100 ml
Specify intravesical rest pressure for 100 ml in centimeters H₂O.
 - Intravesical rest pressure for maximum bladder capacity
Specify intravesical rest pressure for maximum bladder capacity.
- MR-urography
After selecting “MR-urography” you will be asked to answer the following follow-up questions regarding the last MR-urography.
 - Date
Specify month and year of the last MR-urography.
 - Result
Briefly specify result of the last MR-urography.



In case of vesicoureteral reflux, you are asked to specify the degree of the reflux. Please choose one of the following according to the International Grading System for VUR:

Grade I: reflux into a non-dilated ureter.

Grade II: reflux into the renal pelvis without dilatation.

Grade III: reflux into the renal pelvis, moderate dilatation of the upper tract, and minimal blunting of the calyces.

Grade IV: reflux with significant dilatation of the upper tract, moderate ureteral kinking, and blunting of the calyces with preserved papillary impressions.

Grade V: reflux with gross dilatation of the upper tract, ureteral tortuosity, and loss of papillary impressions.

Vesicoureteral Reflux: Classification, Diagnosis, and Treatment (urology-textbook.com) [12.08.2024]

6) Infections

1. Number of verified bacteriuria

Specify number of verified bacteriuria since the last LUTO Follow Up entry.

2. Number of febrile urinary tract infections

Specify number of febrile urinary tract infections since the last LUTO Follow Up entry.

3. Detected bacteria

Select detected bacteria. You can select multiple.

- E. coli
- Enterococcus faecium
- Klebsiella
- Pseudomonas
- Other

Briefly specify other detected bacteria in a free text box.

4. Number of oral/ intravenous antibiotic therapies

Specify number of oral/ intravenous antibiotic therapies since the last LUTO Follow Up entry.

5. Reinfection prophylaxis

Select whether or not any reinfection prophylaxis was taken since the last LUTO Follow Up entry.

7) Dialysis

1. Dialysis treatment

Select whether or not any type of dialysis treatment was performed since the last LUTO Follow Up entry.

- Yes

After selecting "Yes" you will be asked to answer the following follow-up questions regarding dialysis treatment.

- Acute

- Yes

After selecting "Yes" you will be asked to answer the following follow-up questions regarding acute dialysis treatment.

- Date of start

- Specify month and year of start of acute dialysis treatment.
- Type of dialysis
Select type of dialysis used. You can select multiple.
 - ❖ CVVH (continuous veno-venous hemofiltration)
 - ❖ CVVHD (continuous veno-venous hemodialysis)
 - ❖ HD (hemodialysis)
 - ❖ PD (peritoneal dialysis)
- Duration
Specify duration of acute dialysis treatment in days.
- Cause
Select cause for acute dialysis treatment. You can select multiple.
 - ❖ Prerenal
Specify briefly in free text box.
 - ❖ Infection/ sepsis
Specify briefly in free text box.
 - ❖ Postrenal
Specify briefly in free text box.
 - ❖ Other
Specify briefly in free text box.
- No
- Chronic
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding chronic dialysis treatment.
 - Date of start
Specify month and year of start of chronic dialysis
 - Acute cause
Select whether there was an acute cause for the chronic dialysis treatment.
 - ❖ Yes
 - Cause
 - Prerenal
Specify briefly in free text box.
 - Infection/ sepsis
Specify briefly in free text box.
 - Postrenal
Specify briefly in free text box.
 - Other
Specify briefly in free text box.
 - ❖ No
 - Type of dialysis
Select the type of dialysis used for chronic dialysis treatment. You can select multiple.
 - ❖ HD (hemodialysis)
 - ❖ PD (peritoneal dialysis)
 - Residual diuresis

Specify residual diuresis in milliliters/ day.

- No

CVVH = continuous veno-venous hemofiltration

CVVHD = continuous veno-venous hemodialysis

HD = hemodialysis

PD = peritoneal dialysis

8) Surgery

1. Surgery performed

Specify whether or not a surgery was performed since the last follow up entry.

- Yes

After selecting “Yes” you will be asked to answer the following questions regarding possible surgeries.

- No

2. Valve incision

Select whether a valve incision was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding valve incision surgery.

- Date of valve incision

Specify day, month and year of valve incision surgery.

- No

3. Anti-reflux surgery

Select whether or not an anti-reflux surgery was performed since the last LUTO Follow Up entry and if so, which one. You can choose multiple.

- Injection

- Date of injection

Specify day, month and year of injection surgery.

- Side of injection

Select side(s) of injection surgery. You can select multiple.

- Left side

- Right side

- Both sides

- Lich-Gregoir surgery

- Date of Lich-Gregoir surgery

Specify day, month and year of Lich-Gregoir surgery.

- Side of Lich-Gregoir surgery

Select side(s) of Lich-Gregoir surgery. You can select multiple.

- Left side

- Right side

- Both sides

- Gil-Vernet-surgery

- Date of Gil-Vernet surgery

Specify day, month and year of injection surgery.

- Side of Gil-Vernet surgery

Select side(s) of Gil-Vernet surgery. You can select multiple.

- Left side
- Right side
- Both sides
- None

4. Urinary diversion

Select the applicable type of urinary diversion. You can choose multiple.

- Mittrofanoff
 - Date of Mittrofanoff surgery
Specify day, month and year of Mittrofanoff surgery.
- Bladder-skin stoma (non-continent)
 - Date of bladder-skin stoma surgery
Specify day, month and year of bladder-skin stoma surgery.
- Cystofix installation
 - Date of cystofix installation surgery
Specify day, month and year of cystofix installation surgery.
- Ureter-skin stoma
 - Date of ureter-skin stoma installation surgery
Specify day, month and year of ureter-skin stoma surgery.
 - Side of ureter-skin stoma surgery
Select side(s) of ureter-skin stoma surgery. You can select multiple.
 - Left side
 - Right side
- Nephrostomy
 - Date of nephrostomy surgery
Specify day, month and year of nephrostomy surgery.
 - Side of nephrostomy surgery
Select side(s) of nephrostomy surgery. You can select multiple.
 - Left side
 - Right side
- Normal urinary diversion via urethra

5. Nephrectomy

Select whether or not a nephrectomy surgery was performed since the last LUTO Follow Up entry.

- Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the nephrectomy surgery.
 - Date of nephrectomy surgery
Specify day, month and year of nephrectomy surgery.
 - Side of nephrectomy surgery
Select side(s) of nephrectomy surgery. You can select multiple.
 - Left side
 - Right side
 - Reason for nephrectomy
Briefly specify reason for nephrectomy in a free text box.
- No

6. Bladder augmentation

Select whether or not a bladder augmentation surgery was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the bladder augmentation surgery.

- Date of bladder augmentation
Specify day, month and year of bladder augmentation.
- Material used for bladder augmentation
Select material used for bladder augmentation. You can only select one.
 - Bowel
 - Ureter (left side)
 - Ureter (right side)

- No

7. Urethral reconstruction

Select whether or not a urethral reconstruction surgery was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the urethral reconstruction surgery.

- Date of urethral reconstruction
Specify day, month and year of urethral reconstruction.
- Material used for urethral reconstruction
Briefly specify material used for urethral reconstruction in a free text box.

- No

8. Bladder neck incision

Select whether or not a bladder neck incision surgery was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the bladder neck incision surgery.

- Date of bladder neck incision
Specify day, month and year of bladder neck incision surgery.

- No

9. Urethrotomy of stenosis/ strictures

Select whether or not an urethrotomy of stenosis/ strictures was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the urethrotomy of stenosis/ strictures.

- Date of urethrotomy of stenosis/ strictures
Specify day, month and year of urethrotomy of stenosis/ strictures.

- No

10. Orchidopexy

Select whether or not an orchidopexy surgery was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the orchidopexy surgery.

- Date of orchidopexy surgery
Specify day, month and year of orchidopexy surgery.
- Side of orchidopexy surgery
Select side(s) of orchidopexy surgery. You can select multiple.
 - Left side
 - Right side

11. Inguinal hernia surgery

Select whether or not an inguinal hernia surgery was performed since the last LUTO Follow Up entry.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the inguinal hernia surgery.

- Date of inguinal hernia surgery
Specify day, month and year of o inguinal hernia surgery.
- Side of inguinal hernia surgery
Select side(s) of inguinal hernia surgery. You can select multiple.
 - Left side
 - Right side

9) Kidney transplantation

1. Kidney transplantation

Select whether or not a kidney transplantation was performed and if so, specify the point in time. You can only select one.

- Within the last year

After selecting “Within the last year” you will be asked to answer the following follow-up questions regarding the kidney transplantation within the last year.

- Date of transplantation
Specify month and year of the kidney transplantation.
- Transplantation
Select what applies to the transplantation. You can select multiple.
 - Living donor
 - Deceased donor
 - Removal of own kidney(s)
 - Urinary drainage
- Preemptive
Select whether or not the transplantation was preemptive.
 - Yes
 - No
- CKD stage at first discharge after transplantation
Select the CKD stage after the first discharge after the transplantation.

Kidney graft failure

- Kidney graft failure

Select whether or not a kidney graft failure occurred after the transplantation within the last year.

- Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the kidney graft failure after the kidney transplantation within the last year.

- Age at kidney graft failure

Specify age at kidney graft failure in years

- Reason for kidney graft failure

Select reason for kidney graft failure. You can select multiple.

- ❖ Acute rejection
- ❖ Chronic rejection
- ❖ Poliovirus nephropathy
- ❖ (Recurrent) transplant pyelonephritis
- ❖ Reflux nephropathy

Retransplantation

- Retransplantation

Select whether or not the patient has been retransplanted after the kidney graft failure.

- ❖ Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding retransplantation after the kidney graft failure after the kidney transplantation within the last year.

- Time frame of kidney retransplantation

Select time frame of the kidney retransplantation after kidney graft failure.

- Within the last year

After selecting “Within the last year” you will be asked the following questions

- Date of retransplantation
Specify month and year of the kidney retransplantation.
- Retransplantation
Select what applies to the retransplantation. You can select multiple.
 - Living donor
 - Deceased donor
 - Removal of own kidney(s)
 - Urinary drainage
- Preemptive
Select whether or not the retransplantation was preemptive.
 - Yes
 - No
- CKD stage after retransplantation

- Select the CKD stage after retransplantation.
- More than one year ago
 - Current CKD stage after retransplantation
Select current CKD stage after retransplantation
 - Nephrectomy of own kidneys
Select whether or not a nephrectomy of the own kidneys was performed.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the nephrectomy.
 - Cause
Select cause for nephrectomy of own kidneys. You can select multiple.
 - Infection
 - Reflux
 - Proteinuria
 - No
 - Removal of first kidney graft.
Select whether or not the first kidney graft was removed.
 - Yes
 - No
 - Urinary drainage after retransplantation
Select the applicable urinary drainage after retransplantation. You can select multiple.
 - Normal miction via urethra
 - Free residual urine
 - Yes
 - No
 - Cystofix
 - Duration after retransplant
Specify duration after retransplant in days.
 - Single-use catheterization transurethral
 - Mitrofanoff (or other continent stoma)
 - Incontinent bladder skin stoma
 - Ureter skin stoma

- Dilatation of the renal pelvis
Select whether a dilatation of the renal pelvis was observed.
 - Yes
 - Dilatation in degrees
Specify dilatation of renal pelvis in degrees
 - Dilatation in intrarenal pyelon width
Specify dilatation in intrarenal pyelon width in millimeters.
 - No
- Vesicoureteral reflux
Select whether or not vesicoureteral reflux was diagnosed.
 - Yes
 - Grade of vesicoureteral reflux
Select grade of vesicoureteral reflux.
 - No
- Transplant pyelonephritides
 - Yes
 - Number of pyelonephritides
Specify number of pyelonephritides within the last year.
 - No

Kidney graft failure after retransplantation

- Kidney graft failure
Select whether or not a kidney graft failure occurred after the retransplantation.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the kidney graft failure.
 - Age at graft failure after retransplantation
Specify age at graft failure after retransplantation
 - Reasons for kidney graft failure after retransplantation

Select reason for kidney graft failure. You can select multiple.

- Acute rejection
- Chronic rejection
- Poliomyavirus nephropathy
- (Recurrent) transplant pyelonephritis
- Reflux nephropathy

• No

❖ No

▪ No

○ More than one year ago

After selecting “More than one year ago” you will be asked to answer the following follow-up questions regarding the kidney transplantation more than one year ago.

- Current CKD stage after transplantation
Select the current CKD stage after the transplantation more than one year ago.
- Nephrectomy of own kidneys
Select whether or not there has been a nephrectomy of the patient’s kidneys in connection with the transplantation more than one year ago.
 - Yes
After selecting “Yes” you will be asked to answer the following follow-up questions regarding the nephrectomy.
 - Cause
Select cause for nephrectomy of own kidneys. You can select multiple.
 - Infection
 - Reflux
 - Proteinuria
 - No

• Urinary drainage after transplantation

Select the type of urinary drainage used after the transplantation more than one year ago. You can select multiple.

- Normal miction via urethra
After selecting “Normal miction via urethra” you will be asked to answer the following follow-up questions regarding the miction via urethra.
 - Residual diuresis
Select whether or not the patient showed a residual diuresis.
 - Yes
After selecting “Yes” you will be asked to the following follow-up question regarding the residual diuresis.
 - Residual diuresis volume

Specify volume of residual diuresis in ml.

○ No

▪ Cystofix

After selecting “Cystofix” you will be asked to answer the following follow-up questions regarding cystofix.

• Cystofix duration after transplant

Specify the cystofix duration in days after the transplant more than one year ago.

- Single-use catheterization transurethral
- Mitrofanoff (or other continent stoma)
- Incontinent bladder skin stoma
- Ureter skin stoma

• Dilatation of the renal pelvis

Select whether or not there has been a dilatation of the renal pelvis in connection with the transplantation more than one year ago.

▪ Yes

After selecting “Yes” you will be asked to the following follow-up questions regarding the dilatation of the renal pelvis.

• Dilatation in degrees

Specify dilatation of renal pelvis in degrees

• Dilatation in intrarenal pyelon width

Specify dilatation in intrarenal pyelon width in millimeters.

▪ No

• Vesicoureteral reflux

Select whether or not there has been vesicoureteral reflux in connection with the transplantation more than one year ago.

▪ Yes

After selecting “Yes” you will be asked to the following follow-up question regarding the vesicoureteral reflux in connection with the transplantation more than one year ago.

• Grade of vesicoureteral reflux

Select grade of vesicoureteral reflux.

▪ No

• Transplant pyelonephritides

Select whether or not there have been transplant pyelonephritides in connection with the transplantation more than one year ago.

▪ Yes

After selecting “Yes” you will be asked to the following follow-up question regarding the transplant pyelonephritides in connection with the transplantation more than one year ago.

• Number of transplant pyelonephritides

Specify number of transplant pyelonephritides in a free text box.

▪ No

Kidney graft failure

• Kidney graft failure

Select whether or not there was a kidney graft failure after the transplantation more than one year ago.

- Yes
After selecting “Yes” you will be asked to answer the same follow-up questions as the follow-up questions regarding the kidney graft failure after the transplantation within the last year.
Please look above to find those questions.
- No
- Never

10) Further organ functions

1. Functional impairment of the heart

Select whether or not a functional impairment of the heart was observed since the last LUTO Follow Up entry. You can select multiple.

- Impaired ejection fraction
After selecting “Impaired ejection fraction” you will be asked to answer the following follow-up question regarding the impaired ejection fraction.
 - Specify impaired ejection fraction. You can only select one.
 - Mildly abnormal range: LVEF 41-53%
 - Moderately abnormal range: LVEF 30-40%
 - Severely abnormal range: LVEF less than 30%
- Signs of hypertrophy
- None

2. Functional impairment of the lungs

Select whether or not any functional impairments of the lungs have been observed since the last LUTO Follow Up entry. You can select multiple.

- Pneumonias
After selecting “Pneumonias” you will be asked to answer the following follow-up question regarding the pneumonias.
 - Number of pneumonias
Specify number of pneumonias.
- Obstructive bronchitis (oxygen required)
After selecting “Obstructive bronchitis” you will be asked to answer the following follow-up question regarding the obstructive bronchitis.
 - Number of obstructive bronchitis (oxygen required)
Specify number of obstructive bronchitis which required oxygen support.
 - None

3. Functional impairment of the gastrointestinal tract

Select whether or not any functional impairments of the gastrointestinal tract have been observed since the last LUTO Follow Up entry. You can select multiple.

- Constipation (only if requiring treatment)
- PEG-supplied
After selecting “PEG-supplied” you will be asked to answer the following follow-up question regarding the PEG.
 - Cause
Select the reason for the PEG supplementation. You can select multiple.
 - Growth disorder
 - Food refusal

- None

4. Cryptorchism

Select whether or not cryptorchism has been observed since the last LUTO Follow Up entry and if so, select the applicable side. You can select multiple.

- Right side

After selecting “Right side” you will be asked to answer the following follow-up question regarding the cryptorchism on the right side.

- Orchidopexy

Select whether or not an orchidopexy surgery has been performed.

- Left side

After selecting “Left side” you will be asked to answer the following follow-up question regarding the cryptorchism on the left side.

- Orchidopexy

Select whether or not an orchidopexy surgery has been performed.

- None

5. Age-appropriate state of development

Select whether or not the patient has shown age-appropriate development since the last LUTO Follow Up entry.

- Yes

- No

After selecting “No” you will be asked to answer the following follow-up question regarding the not age-appropriate state of development of the patient.

- Intellectual disability

Select whether or not one of the following diagnoses applies to the patient. You can select multiple.

- Motor development delay
- Mental development delay
- Diagnosed ADHD
- Diagnosed autism spectrum disorder
- None

11) Social

1. Kindergarten possible

Select whether or not going to Kindergarten has been possible since the last LUTO Follow Up entry.

- Yes

- No

After selecting “No” you will be asked to briefly specify the cause in a free text box.

12) New diagnosis

1. In a free text box, please specify any diagnosis that has been made since the last LUTO Follow Up entry which has not been queried up until this point.

13) Family

1. Further pregnancies of mother

Select whether or not the mother has had any more pregnancies since the last LUTO Follow Up entry.

Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding further pregnancies of the mother.

- Number of further pregnancies

Select the number of further pregnancies of the mother.

▪ 1

After selecting “1” you will be asked to answer the following follow-up question regarding further pregnancy of the mother.

- Outcome of further pregnancy 1

Select the outcome of the further pregnancy 1.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

▪ 2

After selecting “2” you will be asked to answer the following follow-up question regarding further pregnancies of the mother.

- Outcome of further pregnancy 1

Select the outcome of the further pregnancy 1.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

- Outcome of further pregnancy 2

Select the outcome of the further pregnancy 2.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

▪ 3

After selecting “3” you will be asked to answer the following follow-up question regarding further pregnancies of the mother.

- Outcome of further pregnancy 1

Select the outcome of the further pregnancy 1.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

- Outcome of further pregnancy 2

Select the outcome of the further pregnancy 2.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

- Outcome of further pregnancy 3

Select the outcome of the further pregnancy 3.

- ❖ Early abortion
- ❖ Termination
- ❖ Birth of sibling

No



2. Maternal health condition

In a free text box, please specify any change in the maternal health condition since the last LUTO Follow Up entry.

3. Paternal health condition

In a free text box, please specify any change in the paternal health condition since the last LUTO Follow Up entry.

4. Any abnormalities of kidney/ urinary tract in family

Select whether or not any abnormalities of the kidney or urinary tract have been diagnosed in the family since the last LUTO Follow Up entry.

Yes

After selecting “Yes” you will be asked to answer the following follow-up questions regarding the diagnosis of abnormalities of the kidney or urinary tract in the family.

Person concerned

In a free text box, specify the relation the newly diagnosed relative has to the patient.

Health condition of person concerned

In a free text box, briefly specify the health condition of the newly diagnosed relative.

No