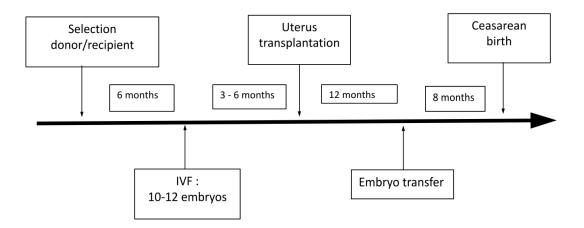
APPENDICES

Appendix 1: Course of a Uterus transplantation protocol

Deadlines are given as an indication only and may vary from one team to another.



Appendix 2: Questionnaire

Opinion survey regarding interest in uterus transplantation in patients suffering from MRKH syndrome.

The gynaecology department of the Rennes University Hospital is willing to develop a uterus transplantation center. In order to know your opinion on such a procedure, we propose you to answer a few questions. It is a mean for us to evaluate the demand on a national scale, but also to give you the opportunity to express your opinion on this matter. This questionnaire is anonymous and quick, and ends with a few informations about the technical aspects of the transplantation. A free text area is available if you have any questions. The study results will be published, and the long-term objective is to highlight the need for a national uterus transplantation program.

Do not leave any comment allowing your identification.

Thank you for your contribution.

Dr Ludivine DION, M.D., obstetrics and gynaecology Pr LAVOUÉ Vincent, M.D.-PhD, Head of the gynaecology department, Rennes University Hospital

Single

Contact: Dr DION Ludivine

• Demographics:

1. How old are you ?

- \circ < 25 years old
- o 25-42 years old
- \circ > 42 years old

2. What is your profession ?

- o Independant
- Employee
- o Student
- o Unemployed
- Other:

4. Do you want to ha	ave a child ?	Yes	No	
5. Do you already have children ?		Yes	No	
6. If so, how ?	Surrogacy	Adoption		

• Condition:

- 7. When and how was the syndrome diagnosed ?
 - Childhood (ultrasound, renal anomaly, other)
 - Adolescence (Amenorrhea, pelvic pain)
 - Beginning of sexual activity (difficulty or impossibility to have penetrative sexual intercourse, other)

Other:

• Other:

8. What is the type of your MRKH syndrome?

- Type 1 (isolated uterovaginal aplasia, no associated condition)
- Type 2 (MRKH syndrome associated with extragenital manifestations: renal, spinal, ENT, other...)
- Other conditio :
- 9. Did you undergo a vagina reconstruction procedure in order to have penetrative sexual intercourse ?

Yes No

If so, how old were you ?

10. What was the reconstructive procedure performed ?

- Nonsurgical method (progressive self-dilation, also known as Frank's method)
- Surgical procedure

11. If a surgical procedure was performed, which one ? utilisée ?

- A procedure using a segment of the digestive tract
- A procedure not using a segment of the digestive tract: is so, which one ?
 - o Davydov
 - o Vecchietti
 - Other:

• Accessing parenthood:

12. What ways of accessing parenthood do you know?

- Adoption
- Surrogacy
- Uterus transplantation

13. Do you feel well informed about these three ways of access to parenthood ?

Yes No

14. Which one of these three possibilities would be your first choice in order to access parenthood ?SurrogacyAdoptionUterus transplantation

• In order to assess your knowledge about uterus transplantation around the world, please answer the following questions:

15. According to you, has uterus transplantation already been performed in women ? Yes No I do not know

16. According to you, has there already been a live birth following a uterus transplantation ?

Yes No I do not know

17. According to you, how many live births has there been around the world, following a uterus transplantation ? Please answer with a number.

18. According to you, the transplanted uterus can be retrieved from:

-	A living donor ?:	Yes	No	I do not know
-	A brain-dead donor ?:	Yes	No	I do not know

19. What is your opinion on uterus transplantation:

I am for it

I am rather for it

I am rather against it

I am against it

No opinion

20. If you are for or rather for uterus transplantation, why ? 1 answer or more

- It allows recipients to bear their own child (i.e. being the bearing mother)
- It allows recipients to have a child sharing the same genetic heritage (i.e. being the biological mother)

- Immunosuppressive therapy is temporary
- Hysterectomy is performed at the end of the pregnancy
- Other:

21. If you are rather against uterus transplantation, why ? 1 answer or more

- The donor is exposed to surgical complications
- The recipient is exposed to a immunosuppressive therapy
- The fetus is exposed to immunosuppressive therapy
- I am scared of the surgery
- Transplantation should be dedicated to vital organs
- Other:

In women, the first successful uterus transplantation was performed in 2001 in Saudi Arabia ; unfortunately, the graft had to be removed after 3 months because of a vascularisation defect. The second success happened in Turkey in 2010: a pregnancy began but an early miscarriage occurred. In 2014, a Swedish team performed a series of nine uterus transplantations: 7 grafts were viable and resulted in the birth of eight healthy children. To this day, more than 50 uterus transplantations were performed worldwide and resulted in the birth of thirteen healthy children.

Before the surgery, the recipient must undergo one or several In Vitro Fertilization cycles in order to obtain at least 10 vitrified embryos.

The graft can be retrieved from a living donor or a brain-dead donor. The transplantation is temporary, and the uterus is kept just the amount of time necessary to complete the pregnancy plan (one or two pregnancies allowed); until then, the recipient is required to undergo immunosuppressive therapy.

For the living donors, surgery lasts several hours (6 to 7 hours) and is performed by an open surgical approach, or more recently by robotic-assisted laparoscopy. Complications may occur (urinary tract wounds, infection, hematoma). Before the surgery, the living donor is asked to undergo a thorough workup with blood tests and pelvic imaging.

For the recipient, the surgery is performed by an open approach (vertical abdominal scar) and lasts approximately five hours. Complications may occur (transplantation failure, hemorrhage, urinary tract wound...). The recipient is closely monitored post surgery, undergoing weekly then monthly cervical biopsies.

If the surgery is a success, menstruation happens approximately six weeks after the transplantation. Embryo transfer can be performed twelve months after the transplantation.

The baby is delivered by ceasarean section. The graft can be used for one or two pregnancies, and immunosuppressive therapy is stopped once the uterus is removed at the end of the pregnancy plan.

22. After reading these informations, has your first choice to access parenthood changed ? Yes No Why:

23. If so, what is your first choice now ? Surrogacy Adoption Uterus transplantation

24. Did you discuss uterus transplantation with other teams in France ? Yes No

If so, which team(s)?

25. Did you try to get involved in the Limoges university Hospital trial (Pr Gauthier) on uterus transplantation ?

Yesi No

26. Would geographic distance between your home and the uterus transplantation center be an obstacle to your participation in such a project ?

Yesi No I do not know

27. Regarding the funding of uterus transplantation, estimated to cost 100 000 euros (pre-surgery workup, immunosuppressive therapy, surgery and monitoring, do you think it should be :

- entirely funded by Social Security
- funded in part by Social Security
- o funded in part/mostly by the patient (recipient)
- o entirely funded by the recipient

28. Do you think funding could consist of donations ("crowdfunding" or national campaign, other ?)

Yes No I do not know