

Transition within Immunology Services

Please answer every question as best as possible. The questionnaire needs to be completed and submitted in one sitting. Thank you.

1. Email address *

Centre Details

2. Hospital:

3. City:

4. Country:

5. Lead clinician:

6. Referral base (tick all that apply):

Check all that apply.

- Local
- Regional
- National
- Unknown
- Other:

7. Are you completing this for: (If both, please fill in a separate questionnaire for each, and indicate your response for the current questionnaire. To access an additional copy of the form, click the link in the original email for a second time once you have submitted the current one.)

Mark only one oval.

- Primary Immunodeficiency Disease
- Autoinflammatory Disorders

8. What number of paediatric patients with this condition are cared for at your centre?*Mark only one oval.*

- <50
- 50-100
- 100-200
- 200-500
- >500
- Unknown

9. What number of patients aged 12-18 with this condition are cared for at your centre?*Mark only one oval.*

- <50
- 50-100
- >200
- Unknown

10. What number of patients do you transfer to adult services each year?*Mark only one oval.*

- <5
- 5-10
- 10-20
- 20-40
- >40
- Unknown

Transition Process

11. Where do you refer paediatric patients for adult care?*Check all that apply.*

- Specialist adult PID/autoinflammatory centre
- General adult rheumatology clinic
- Adult internal medicine physician
- General practitioner
- Discharge without specific follow up
- Other adult clinic
- Unknown

12. Do you have formal transition partner(s)?*Mark only one oval.*

- Yes
- No

13. What proportion of your patients transition to your formal transition partner?

Mark only one oval.

- >75%
- 50-75%
- 25-50%
- <25%
- Unknown
- Not applicable

14. Do you have a defined process for transition?

Mark only one oval.

- Yes
- No

15. Do you have national disease-specific guidelines for transition?

Mark only one oval.

- Yes
- No

16. Do you follow these at your centre?

Mark only one oval.

- Yes
- No
- Partially

17. Does your transition program include patients who have had Hematopoietic Stem Cell Transplantation in childhood?

Mark only one oval.

- Yes
- No
- Not yet (future aspiration)

18. Who chooses the adult centre? (tick all that apply, eg where decision is a consensus)

Check all that apply.

- The medical team
- The parents
- The patient
- No choice: there is only one centre available
- Funder (eg health insurance)
- Unknown
- Not applicable

19. What influences your choice of adult centre? (tick all that apply)*Check all that apply.*

- Expertise of the adult team
- Other services available at that centre
- Local location for the patient
- Professional connection with the adult team
- Funding options
- Unknown
- Not applicable

20. Compared to the paediatric centre, is the adult centre usually:*Mark only one oval.*

- Further from the patient's home
- Similar distance from the patient's home
- Nearer to the patient's home
- Variable for each patient
- Unknown
- Not applicable

21. Do you have difficulty identifying a specialist centre for adult care?*Mark only one oval.*

- Yes
- No

22. If yes, what are the reasons? (tick all that apply)*Check all that apply.*

- Lack of specialist adult centres
- Lack of engagement from existing/specialist adult services
- Distance for the patient to travel to a specialist centre
- Lack of funding for follow up of adult patients
- Unknown
- Not applicable
- Other: _____

If a transition program is in place:

23. What median age does this start at?*Mark only one oval.*

- 10-12
 12-14
 14-16
 16-18
 18 or over
 Unknown
 Not applicable

24. What median age does this end at?*Mark only one oval.*

- 10-12
 12-14
 14-16
 16-18
 18-20
 >20
 Unknown
 Not applicable

25. At what age do you transfer to the adult centre?*Mark only one oval.*

- 12-14
 14-16
 16-18
 18-20
 >20
 Unknown
 Not applicable

26. What material/program do you use?

27. What factors influence age of transfer? (tick all that apply)*Check all that apply.*

- End of transition program
- Patient considered to be ready for transition
- Medically stable
- Age of the patient
- Paediatric centre can no longer offer care
- Unknown
- Not applicable
- Other: _____

28. Are patients transitioned to intermediate adolescent services prior to moving to the adult service?*Mark only one oval.*

- Yes
- No

29. Do you have joint clinics with the adult team prior to transfer to adult care?*Mark only one oval.*

- Yes
- No

30. If yes, how many joint appointments occur per patient?

31. Do you have the ability for virtual joint clinics between paediatric and adult teams?*Mark only one oval.*

- Yes
- No

32. If yes, please give further details:

33. Does the adult centre have a designated young adult clinic?*Mark only one oval.*

- Yes
- No

34. What professionals are involved in the transition process? (tick all that apply)*Check all that apply.*

- Paediatric physician
- Adult physician
- Nurse
- Psychologist
- Youth Worker
- Social Worker
- Pharmacist
- Specialists from other medical teams
- Unknown
- Not applicable
- Other

35. If 'specialists from other medical teams' or 'other', please specify here:

36. What professionals are involved in the transfer appointment? (tick all that apply)*Check all that apply.*

- Paediatric physician
- Adult physician
- Nurse
- Psychologist
- Youth worker
- Social worker
- Pharmacist
- Specialists from other medical teams
- Other
- Unknown
- Not applicable

37. If 'specialists from other medical teams' or 'other', please specify here:

38. What information is transitioned to the adult team? (tick all that apply)

Check all that apply.

- Transition letter
- Full medical history including co-morbidities
- Imaging files
- Relevant test results (eg blood/lung function)
- Vaccination history
- Details of conditioning and donor if HSCT
- Genetic report
- Family pedigree
- Psychological well-being/mental health
- Learning disability/educational needs
- Education/occupation plan
- Social work involvement
- Medication details
- Specific issues about procedure fears (eg needlephobia)
- Unknown
- Not applicable
- Other: _____

39. Is there full integration of records between paediatric and adult services (eg electronic case record)?

Mark only one oval.

- Yes
- No

40. Do you have dedicated administrative time (e.g. a secretary) to prepare transition documents?

Mark only one oval.

- Yes
- No

41. Prior to transfer do you specifically discuss the following with the patient? (tick all that apply)

Check all that apply.

- Understanding of disease
- Genetic basis and heritability
- Fertility and parenthood (if previous HSCT)
- Contraception and sexual health
- Substance use (alcohol/drugs)
- Understanding of current medications
- Compliance with current treatment regimen
- Preference for transition centre
- Expectations of adult services
- Patient responsibility for own health care
- Mental health and well-being
- Vocational expectations (work and education planning)
- Life expectancy
- Health insurance
- Unknown
- Not applicable

42. What, in your opinion, are the main weaknesses of your transition program? (tick all that apply)

Check all that apply.

- Lack of suitable centres to transition to
- My patients do not want to engage
- I do not have engagement from the paediatric team
- I do not have engagement from the adult team
- I do not have time to prepare the documentation
- Medication that the patient is receiving is not available in the adult centre
- Lack of resource and funding for transition within the adult service
- Fragmentation of services in adult centres
- Lack of holistic care at the paediatric centre (eg psychology)
- Lack of holistic care at the adult centre (eg psychology)
- Unknown
- Not applicable
- Other: _____

43. Do you have keep a database of transitioned patients?

Mark only one oval.

- Yes
- No

44. Do you have any transition-specific research program in your department?

Mark only one oval.

Yes

No

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