

Co-created explanations of alopecia biology and RNA-based treatments

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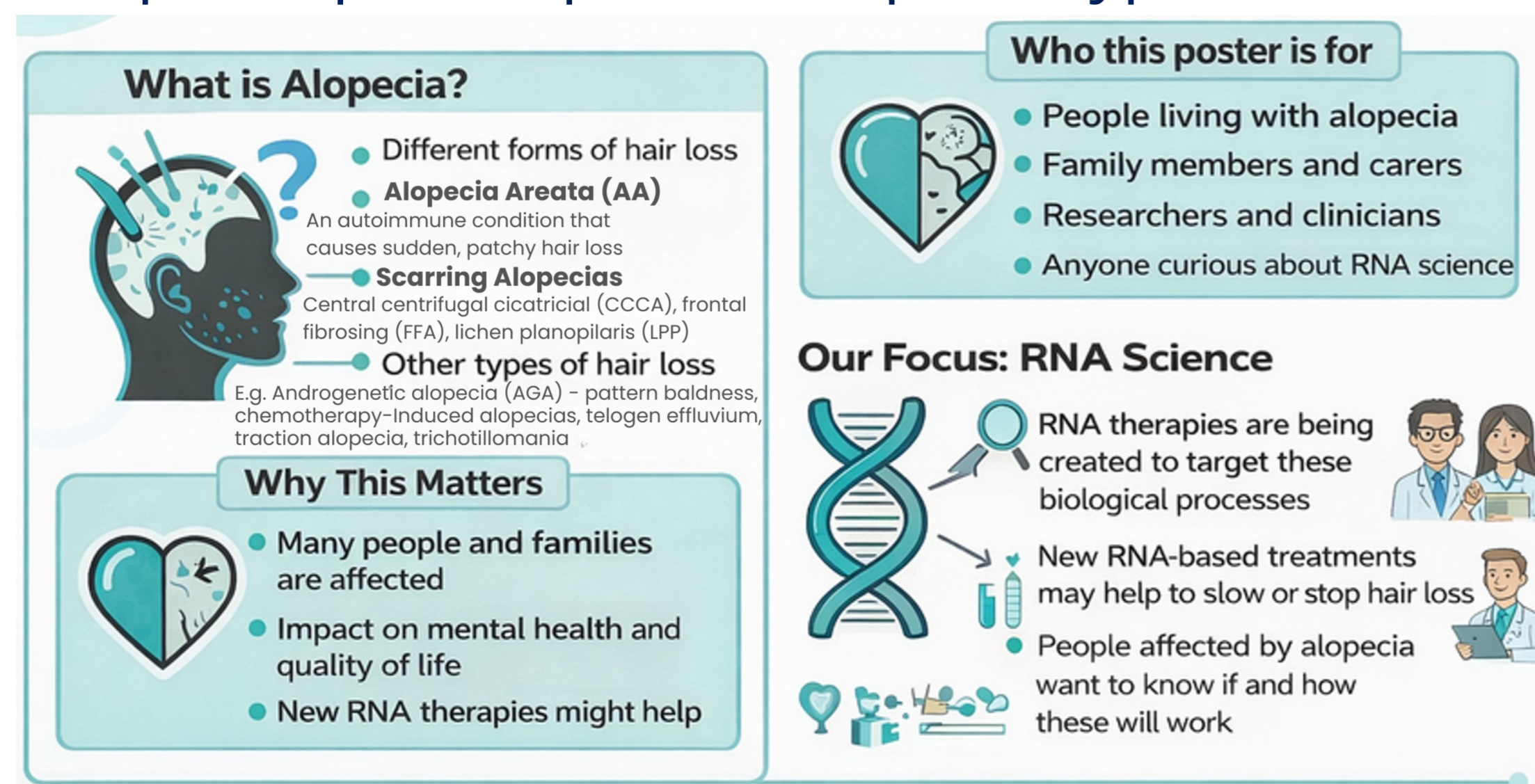
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Introduction

Alopecia is a hair loss condition with notable psychological and social impact^{1,2}. Patient perspectives are under-represented, making patient and public involvement and engagement (PPIE) in research key to linking lived experience with advances in hair biology and RNA*-based approaches³.

The RNA Bioscience for Participatory Alopecia Research (RNA-PAR) project addresses this by involving people with alopecia as co-researchers, ensuring research is relevant, responsible and aligned with stakeholder expectations (Fig. 1 shows participant-reported alopecia types; n=163).



Methods

- We employed a participatory research approach throughout⁴, drawing on established co-production frameworks in health research and the UK Standards for Public Involvement.
- Co-researchers with lived experience of different types of alopecia were involved across all stages of the project, contributing to study design, interpretation and outputs. They received remuneration and/or tokens of appreciation for their time, skills and expertise in line with LJMU policy and NIHR guidance.
- Data were informed by a review of existing literature, qualitative and mixed-methods social listening (QMSL), co-creation workshops and an anonymous online survey (Ethics Reference: 25/PBS/005).
- This poster was co-created by people with lived experience of alopecia.

*Ribonucleic acid (RNA) is a versatile, typically single-stranded nucleic acid molecule essential for life, responsible for carrying genetic instructions, regulating genes, and building proteins.

Results and Discussion

- Through co-creation, we learned that alopecia is experienced very differently across individuals and over time.
- Consistent with existing qualitative alopecia literature, some described alopecia as identity-shaping and manageable or neutral; many people move between these perspectives as their circumstances changed².
- Co-producing RNA-based visuals with those affected by alopecia makes complex molecular mechanisms accessible (Fig. 2).
- These materials are grounded in lived experience, challenging purely researcher-led models⁵.

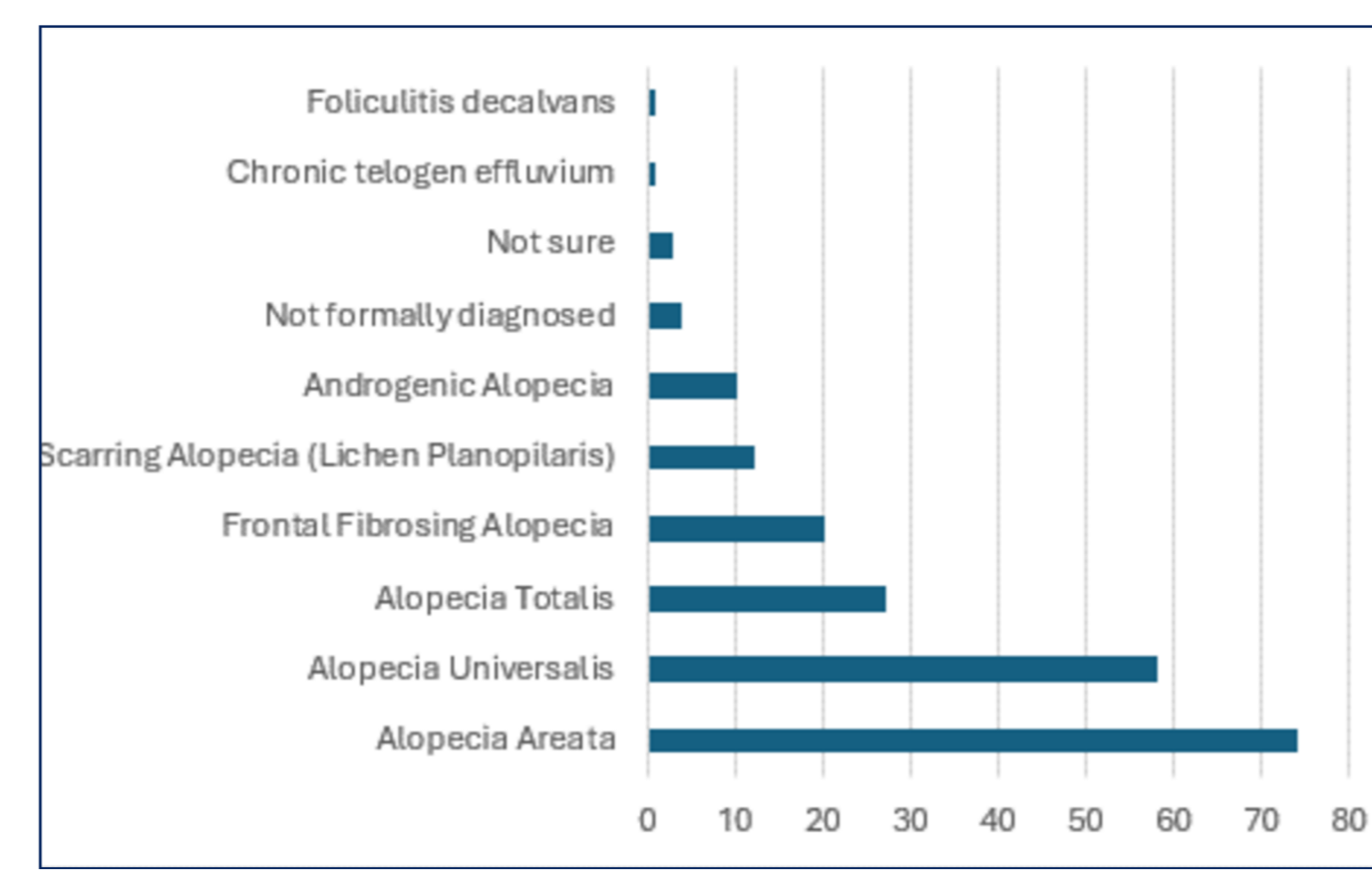


Fig 1: Types of Alopecia represented in the RNA-PAR study, with distribution expressed as a percentage of total study population

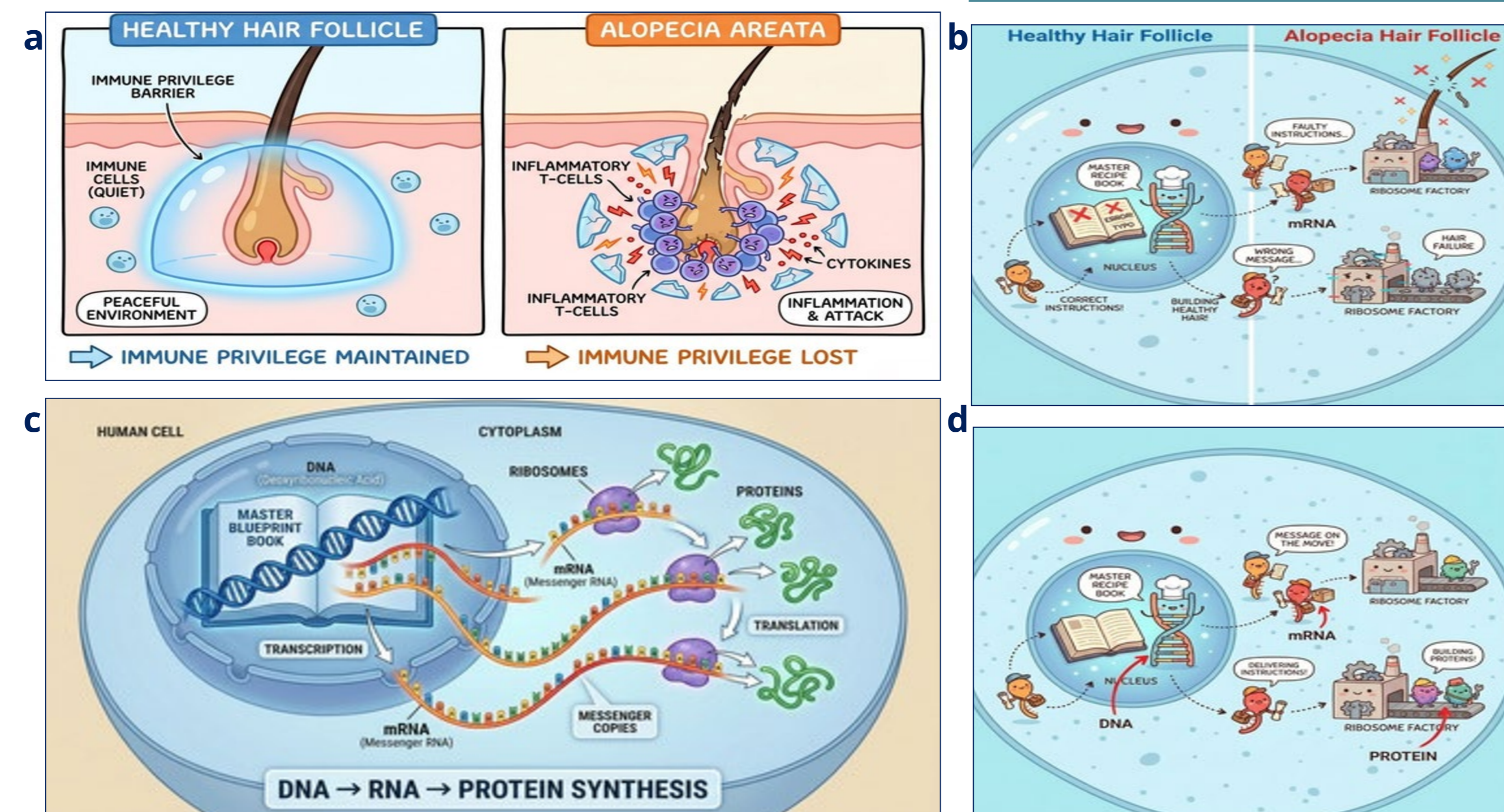


Fig 2: Selected co-created outputs. (a) immune privilege in alopecia areata, (b) healthy vs alopecia hair follicle, (c) expanded protein synthesis process, (d) simplified protein synthesis process.

- Limitations:** We acknowledge that some perspectives are under-represented given that we struggled to reach ethnically diverse populations and males.
- Future work** should test and adapt these resources with broader and more diverse groups³ and evaluate how they influence understanding, hope and decision-making about emerging RNA-based treatments

Co-creating Biological Explanations

People living with alopecia worked alongside researchers to shape how alopecia biology and RNA-based mechanisms were explained. Participants reviewed early drafts of diagrams and language, identifying where explanations felt overly technical, misleading or disconnected from lived experience. Changes focused on:

- Simplifying visual pathways without losing scientific accuracy
- Making uncertainty and research limits visible
- Connecting molecular processes to everyday

Conclusion

We co-developed patient-centered scientific materials to effectively communicate alopecia biology and RNA-based approaches. These outputs helped bridge molecular biology and everyday experience.

Next steps include sharing our posters and gathering feedback to refine how RNA research is explained for different types of alopecia.

Patient voices will remain central in guiding decisions for the research and development of RNA-based treatments for alopecia.

In Our Words: What We Want Future Researchers to Do

PATIENT VOICE RECOMMENDATIONS

- Treat alopecia as MORE than appearance**
- Increase diversity & inclusion**
- Be honest about RNA treatments**
- Make work accessible to ALL**
- Prioritize participant wellbeing**
- Co-create with patients**
- Use plain, clear language**
- Offer long-term follow-up**
- Share findings openly & quickly**

Fig 3: Priorities reflecting what mattered most to RNA-PAR participants

Acknowledgements

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