

## The RNA World Hypothesis to Lived Experience: Co-creating RNA Futures for Alopecia

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### Introduction

RNA\* is a powerful biological molecule that is central to many significant medical advances of the 21<sup>st</sup> century<sup>1,2,3</sup>. Approved RNA-based therapies illustrate the transition from theoretical RNA biology to routine clinical practice (Fig 1). Although RNA-based treatments are transforming care for conditions, patient awareness, trust and communication preferences remain under-explored.



Fig 1: Approved RNA-based therapies (a) COVID-19 messenger RNA vaccine<sup>2</sup>, (b) small interfering RNA therapeutic, rivfloza, for primary hyperoxaluria<sup>3</sup>.

The RNA Bioscience for Participatory Alopecia Research (RNA-PAR) project addressed this gap by working alongside people with lived experience of alopecia.

Here, we can begin to understand their awareness of RNA, perspectives on treatment and information requirements.

Through co-creation, we explore the history of RNA and current technologies, while gaining insight into lived experience perspectives of RNA science.

### Methods

Co-researchers with lived experience of different types of alopecia collaborated throughout the project, contributing to design, interpretation and outputs.

Data were informed by a review of existing literature, qualitative and mixed-methods social listening (QMSL), co-creation workshops and anonymous online survey (Ethics Reference: 25/PBS/005) Outputs were co-produced with adults in the UK living with different types of alopecia, including this poster.

\*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

RNA is central to early life processes as proposed by the RNA World Hypothesis, suggesting it stored genetic information and catalyzed reactions before DNA and proteins<sup>4,5,6,7</sup>.

RNA-PAR participants acknowledged this continuity, linking RNA's origins to its current medical uses, which helps reframe it as familiar rather than futuristic by reducing perceptions of “unnaturalness” (Fig 2).

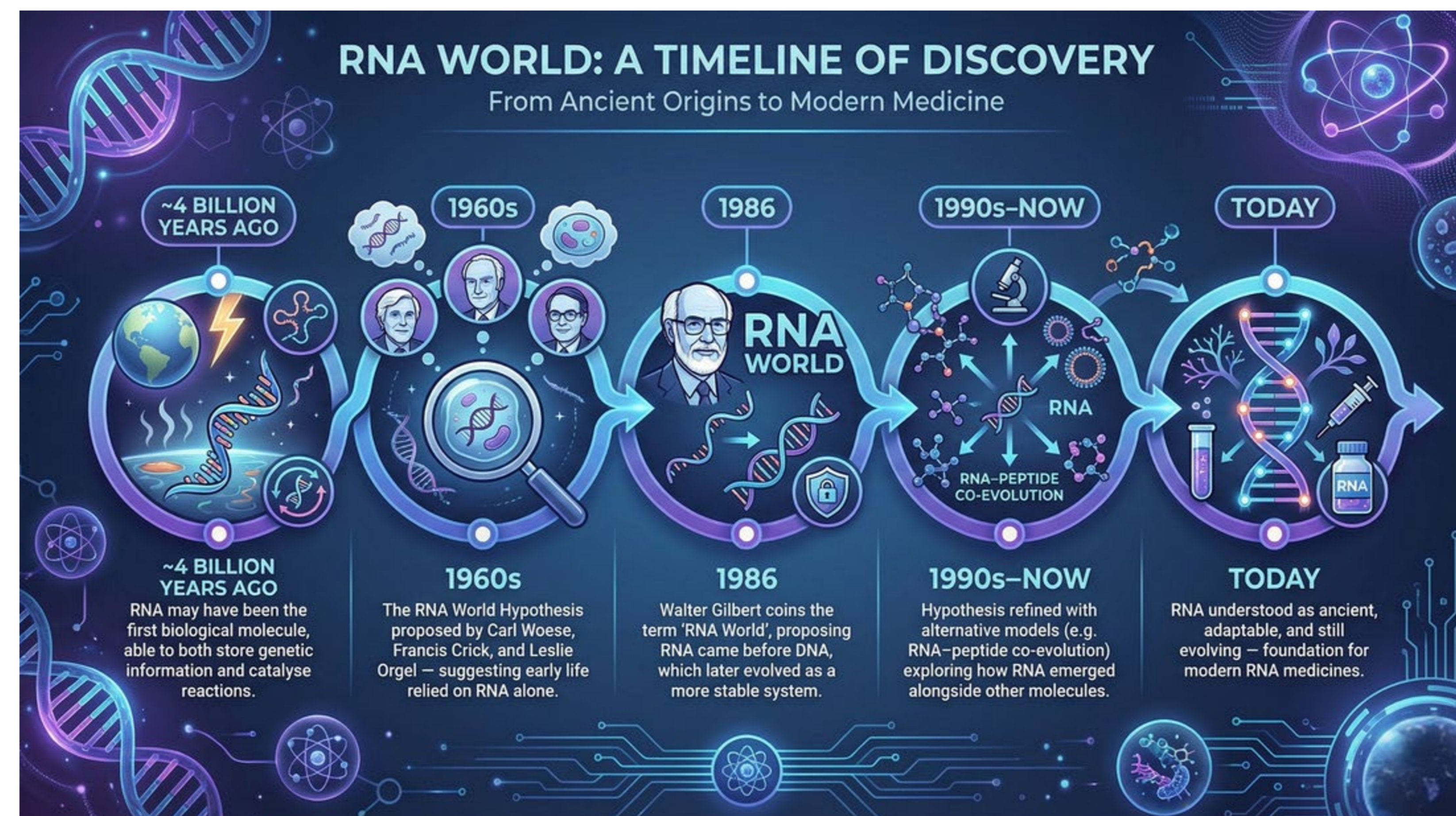


Fig 2: RNA World: a timeline of discovery. Created with Chris Docherty (lived-experience co-researcher).

Participants consistently emphasized the importance of plain language, a desire for realistic expectations and the value of being included earlier in research. We found awareness of RNA science to be low but interest high, with nuanced and thoughtful views on emerging therapies (Fig 3). Linking modern therapies to the RNA World Hypothesis

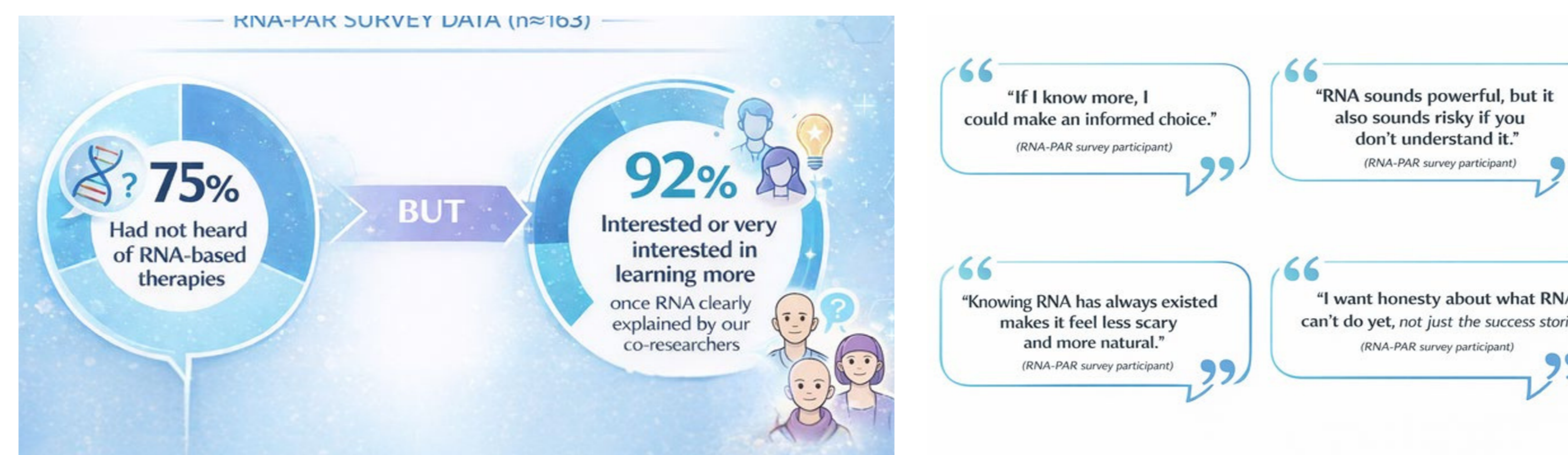


Fig 3: Awareness of and interest in RNA (n=163; RNA-PAR Survey Data 2025).

### Conclusion

RNA-based therapeutics are now an established and rapidly expanding class of medicines, enabled by advances in RNA chemistry, delivery systems and manufacturing<sup>1</sup>.

RNA-PAR demonstrates that co-creation is not an add-on to this progress but a mechanism for better science: as RNA medicines emerge, public understanding and confidence depend on upstream patient and public involvement that prioritises transparency, lived experience and bio-psycho-social impact alongside molecular function.

#### Key insights from RNA-PAR

Scientific maturity does not guarantee public confidence

Molecular efficacy alone is insufficient

Engagement introduced late limits impact

Ethical translation requires more than compliance

Trust grows through open discussion of risks, unknowns and limits

Patient priorities include identity, mental health, well-being and daily life

Lived experience helps embed equity, relevance and responsibility



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