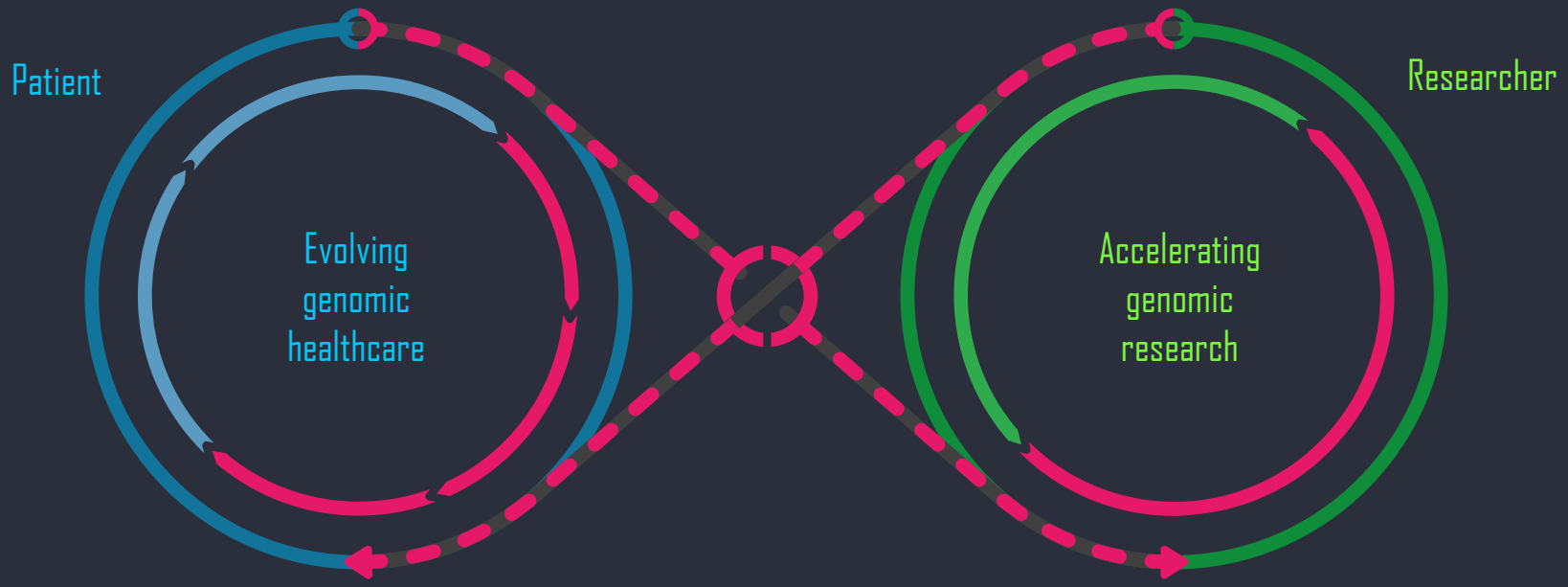
PART 2:

Patient voices and Genomics England

Genomics England's mission (from a patient perspective)

- **Curating the National Genomics Research Library**
- **Working with the National Health Service** to diagnose more genetic disorders and gain a better understanding of cancer
- **Encouraging more researchers** to come and analyse this data
- **Better scientific knowledge** will help to develop better health care for patients, which will drive further innovation: 'infinity loop'

Genomics England Infinity Loop



Patients

Healthcare teams

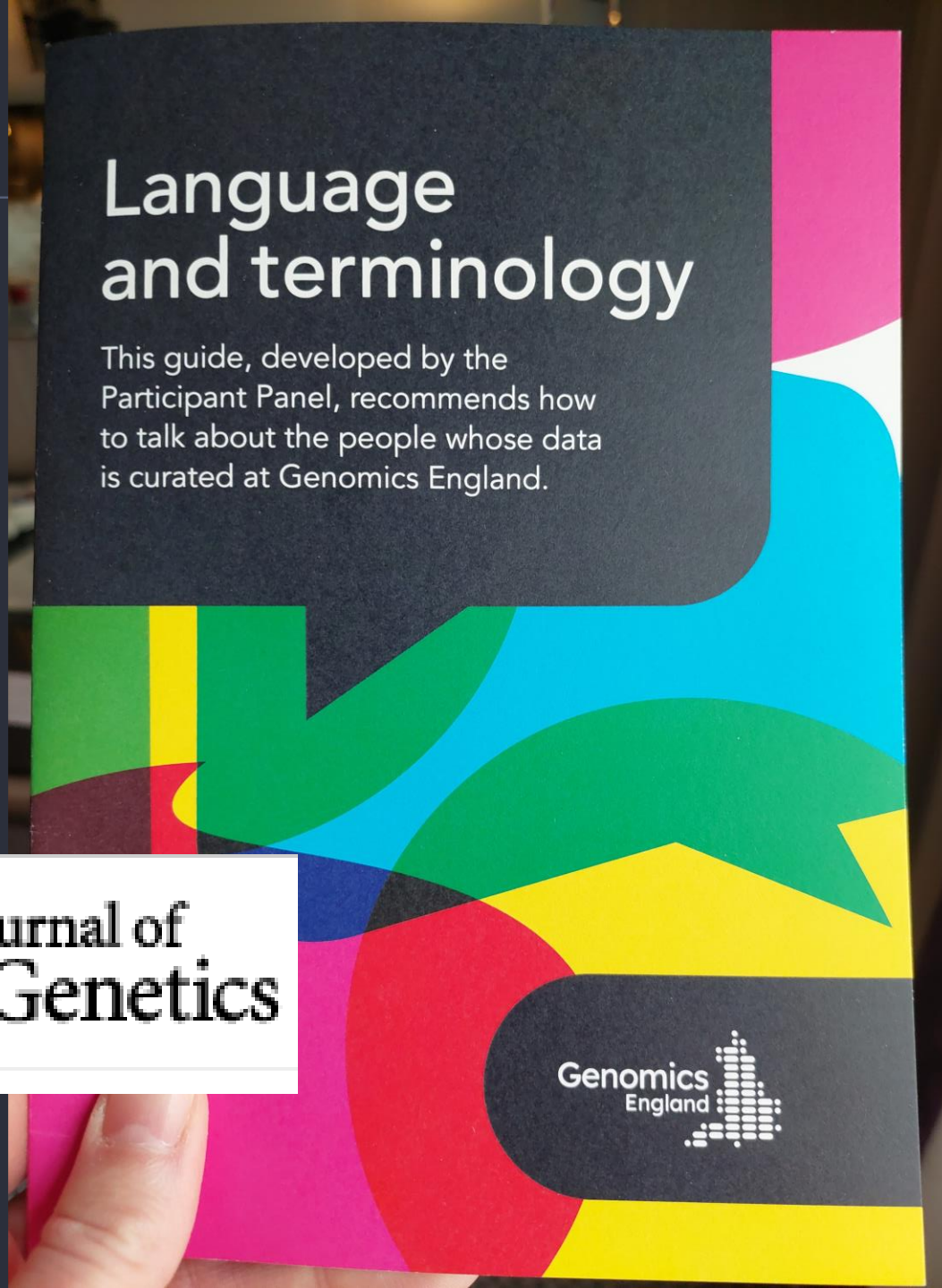
Researchers

How research participants are involved

- Participant Panel since 2016
- Lived experience of rare diseases and cancers
- Meet 4 times a year with Chief Exec, Chief Scientist and other senior leaders
- Direct reporting line to the Board
- Panel members also sit on other decision-making groups in Genomics England

Examples of Panel impact

European Journal of Human Genetics



Top 5 tips for involving patients and family members

1. Build trust, and manage expectations: acknowledge the inherent risks and limitations in genomics / personalised medicine
2. Invite patients and family members to discuss your plans from an early stage, and offer to pay them for their time
3. Invite them to comment on something specific, but also offer them the flexibility to challenge you if they can see a different need for improvement
4. Listen to them, and adjust your plans where necessary
5. Build long term relationships: patients and their families are invested in the outcomes

Thank you

Happy to take any further questions!

Please email:

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