

# Patient and Public Involvement Co-Development of a Route to Record-Level Data Access to Akrivia Health's Secondary Healthcare Dataset

*A patient-centred approach to mental health medical data access*



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Special thanks to our PPI team

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## BACKGROUND

Using electronic health records (EHRs) as a source of real-world health data in research has vast potential for public good<sup>1</sup>, however, data sharing often raises concerns among patients<sup>2</sup>, particularly in the mental health domain<sup>3</sup>.

## AIM

To co-develop with our Patient and Public Involvement (PPI) team a record-level data access (RLDA) model for third-party researchers to Akrivia Health's anonymised\* psychiatric EHR dataset of >4million patients; integrating patients' attitudes and expectations around health data sharing for research into this RLDA model.

\*data that has been assessed and determined that it is reasonably unlikely to relate to a living individual who can be identified

## METHODS

### Attendees

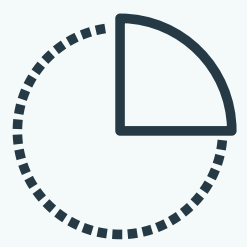


Head of IG &  
2 researchers

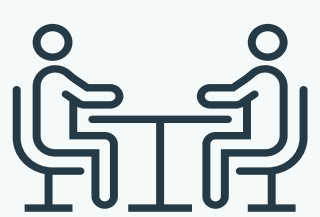


PPI team  
6 attendees

### Session 1



3h

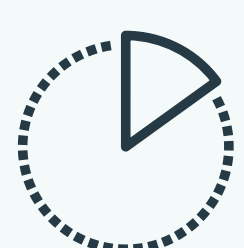


In person

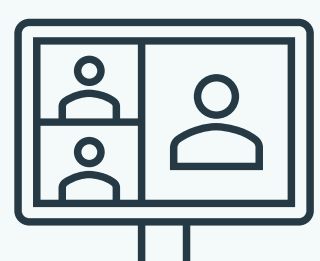
#### Topics

- Record-level data
- Example use cases
- Steps to access
- Perceived benefit
- Addressing common concerns

### Session 2



2h



Remote

#### Topics

- Record-level data
- Secondments
- Steps to secondment
- Estimated costs

### Feedback formats



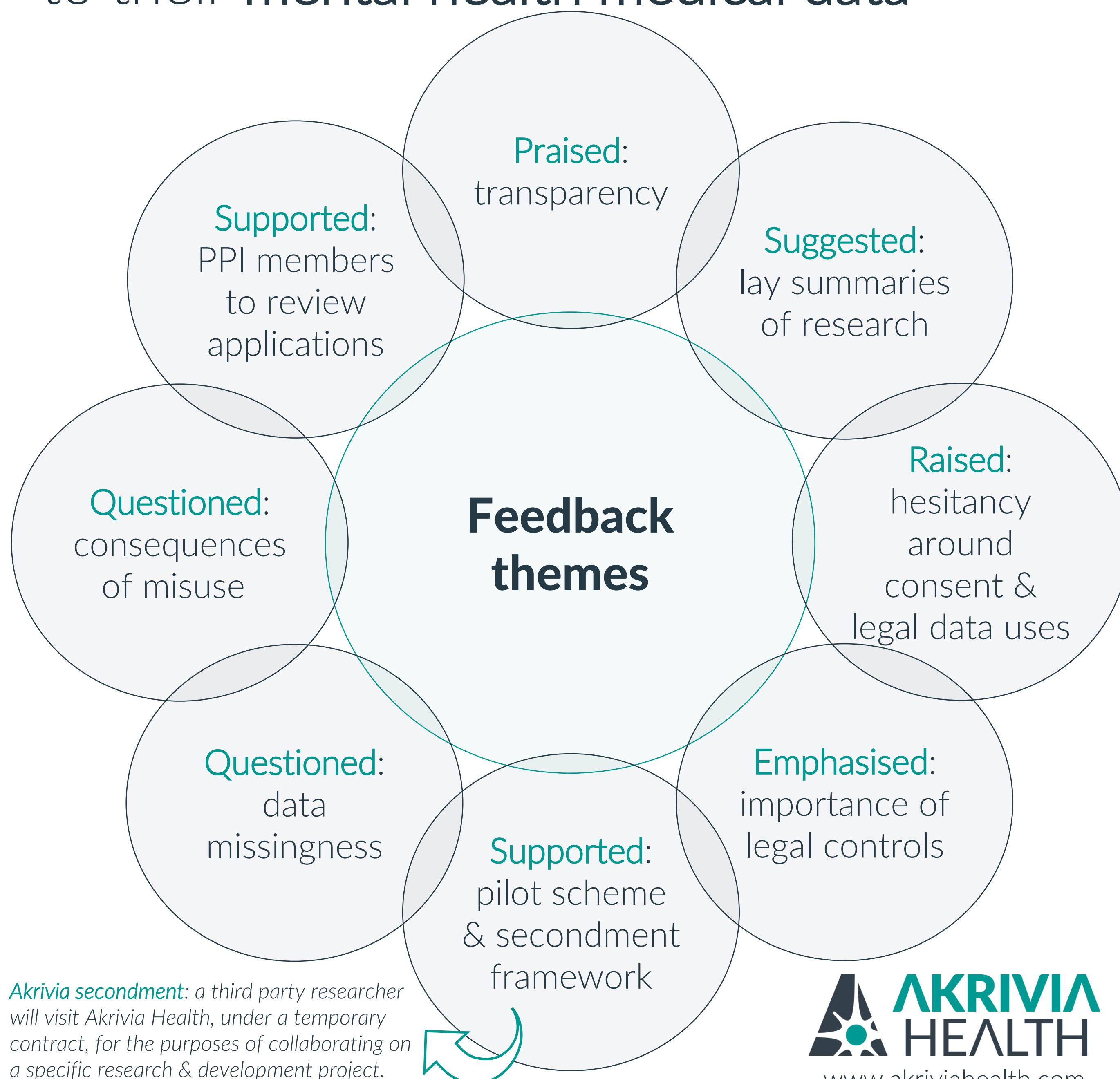
Group  
discussions



Written forms  
Including 5-point Likert scale  
(very negative to very positive)

## RESULTS

Patients value transparency and involvement regarding research access to their mental health medical data



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## CONCLUSION

- Most PPI members (4/6) were “very positive” in response to opening record-level data access for researchers (2/6 “quite positive”).
- Members helped shape steps to access (e.g. inclusion of lay summaries) and were in favour of ongoing involvement in a transparent RLDA model (e.g. reviewing applications).

## FUTURE DIRECTIONS

- Committing to addressing topics of consent, consequences of misuse, and data missingness.
- Pursuing co-development of pilot scheme via secondment framework.

## REFERENCES

1. Aitken, M., Porteous, C., Creamer, E., & Cunningham-Burley, S. (2018). Who benefits and how? Public expectations of public benefits from data-intensive health research. *Big Data & Society*, 5(2), <https://doi.org/10.1177/2053951718816724>
2. Ford, E., Rees-Roberts, M., Stanley, K., Goddard, K., Giles, S., Armes, J., ... & Cassell, J. (2020). Understanding how to build a social licence for using novel linked datasets for planning and research in Kent, Surrey and Sussex: results of deliberative focus groups. *International journal of population data science*, 5(3), <https://doi.org/10.23889/ijpds.v5i3.2114>
3. Gillard, S., Simons, L., Turner, K., Lucock, M., & Edwards, C. (2012). Patient and public involvement in the coproduction of knowledge: reflection on the analysis of qualitative data in a mental health study. *Qualitative Health Research*, 22(8), 1126-1137. <https://doi.org/10.1177/1049732312448541>