



Better health, better futures

A researcher's journey to accessing patient data: a Scottish perspective

Dr Elizabeth Lemmon

 @ElizabethLemm

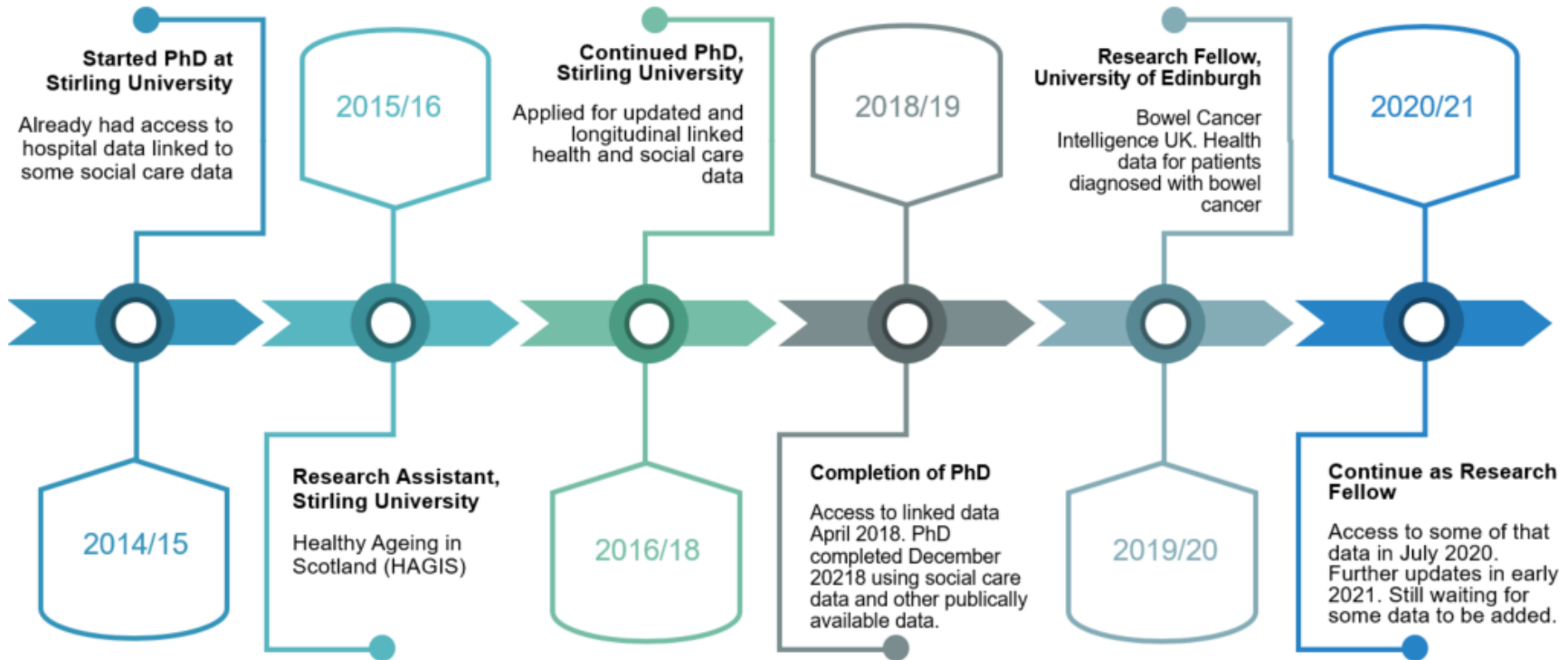
Edinburgh Health Economics



THE UNIVERSITY
of EDINBURGH

 **usher**
institute

My patient data journey



Accessing patient data in Scotland

- All applications for NHS Scotland health data go through the Public Benefit and Privacy Panel for Health and Social Care (PBPP)
- Their role is *“to ensure that applicants have thought through the public benefit and privacy implications of the proposal”*
- Researchers approach the Electronic Data Research and Innovation Service (eDRIS) with their proposal and they are assigned a Research Coordinator
- Cost determined by the size of the study (£6,000-£22,000)

The challenges

- **Timing**

- Pre-PBPP submission
- Post-PBPP approval

- **Availability/accessibility of information**

- Timing
- The data
- Training
- PBPP application



www.ecrusad.co.uk

Including the patient voice in my research

International Journal of Population Data Science (2021) 6:1-10



International Journal of Population Data Science



Journal Website: www.ijpds.org

Creation of the first national linked colorectal cancer dataset in Scotland: prospects for future research and a reflection on lessons learned

Catherine R Hanna¹, Elizabeth Lemmon², Holly Ennis³, Robert J Jones¹, Joy Hay⁴, Roger Halliday⁵, Steve Clark⁶, Eva Morris⁷, and Peter Hall⁸

2017. Project number:SG000-000850. This work uses data provided by social care service users and collected by the Scottish Government as part of their care and support.



People Make Data Blog Series

g series is a series of blog posts that are focussed on the use of people's data in research. We hear from moting the safe use of patient data for research, we also talk to the people behind the data to find out data should be used.

Next steps

- Promoting the inclusion of the patient/public voice among early career researchers in Scotland
- Especially among social researchers
- Information for researchers